# AMERICAN INDIAN AND ALASKA NATIVE ELIGIBILITY AND ENROLLMENT IN MEDICAID, SCHIP, AND MEDICARE

### INDIVIDUAL CASE STUDIES FOR TEN STATES

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by Kathryn Langwell, Project Director, Mary Laschober, Task Leader, Erika Melman and Sally Crelia

Federal Project Officers: Arthur Meltzer and Linda Greenberg

BearingPoint, Inc. and Westat, Inc.

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The Statements contained in this report are solely those of the authors and do not necessarily reflect the views or policies of the Centers for Medicare & Medicaid Services. The contractor assumes responsibility for the accuracy and completeness of the information contained in this report.

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#### **DISCLAIMER**

The comments and recommendations contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or to determine the feasibility of the recommendations. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services, the Indian Health Service, individual States, or individual Tribes or Tribal organizations.

<sup>&</sup>lt;sup>1</sup> Kathryn Langwell, Project Director, was with Project HOPE when the contract began but is now employed at Westat, Inc.

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#### CHAPTER I. OVERVIEW

#### **OVERVIEW OF STUDY**

In September 2001, the Centers for Medicare & Medicaid Services (CMS) funded a two-year study to examine barriers to enrollment of American Indians and Alaska Natives (AI/ANs) in Medicaid, State Children's Health Insurance Programs (SCHIP), and Medicare (including the Medicare Savings Programs),<sup>2</sup> and to identify strategies that may be effective in encouraging and facilitating AI/AN enrollment in these programs. The primary objectives of the project – conducted jointly by BearingPoint, Project HOPE's Center for Health Affairs,<sup>3</sup> and Social and Scientific Systems, with assistance from six American Indian consultants and a nine-member Technical Expert Panel (TEP)<sup>4</sup> – were to:

- 1. Estimate eligibility for, and enrollment of, AI/ANs in the Medicaid, SCHIP, and Medicare programs in 15 selected States; and
- 2. Conduct in-depth case studies in 10 of the 15 States to identify both barriers to enrollment and effective strategies for addressing these barriers in order to increase program enrollment among AI/ANs.

For the case study component of the project, site visits were conducted in 10 States: Alaska, Arizona, Michigan, Minnesota, Montana, North Dakota, Oklahoma, South Dakota, Utah, and Washington. In each State, interviews were conducted with Tribal leaders, Tribal health directors, Indian Health Service (IHS) Area and Service Unit staff, State Medicaid and SCHIP officials, Urban Indian Health Center staff, State/County eligibility and outreach workers, and other organizations and individuals knowledgeable about AI/AN health care and access issues. Draft individual case study reports were prepared for each State following the site visits and follow-up telephone interviews. These draft individual case studies were circulated to key contacts in each Tribe, State Medicaid and SCHIP office, Urban Indian Health Clinic, and other organizations that participated in interviews for review and comment. Comments, including corrections and additions, from interviewees in each State were incorporated into the draft State case studies, which were then sent to CMS for review and comments. The CMS project officer circulated the draft case study reports to additional reviewers within CMS and IHS. This final report contains the Individual Case Studies for the 10 States that reflect input and comments received from all reviewers.

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<sup>&</sup>lt;sup>2</sup> The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

<sup>&</sup>lt;sup>3</sup> Kathryn Langwell, Project Director, was with Project HOPE when the contract began but is now employed at Westat, Inc.

<sup>&</sup>lt;sup>4</sup> Appendix I.A lists Technical Panel members and project consultants who contributed to the study.

<sup>&</sup>lt;sup>5</sup> Appendix I.B lists Tribes, Tribal organizations, Urban Indian Health Clinics, and other organizations interviewed in each of the 10 States. Appendix I.C includes a copy of the Interview Guide used for all interviews in the 10 States.

In addition to the final report on Individual Case Studies for Ten States, the project team prepared a Summary Case Study Report that synthesizes and analyzes the information presented in the Individual Case Studies for Ten States, a Data Analysis Report that presents findings from the data compilation and analysis of eligibility and enrollment of AI/ANs in Medicaid, SCHIP, and Medicare, and a Final Report on AI/AN Eligibility and Enrollment in Medicaid, SCHIP, and Medicare.

#### RESEARCH QUESTIONS AND METHODS

The case study component of the project was designed to obtain information on barriers to AI/AN enrollment in Medicaid, SCHIP, and Medicare and, to the extent possible, to assess the relative importance of each enrollment barrier as indicated by those interviewed during the site visits. An additional goal of the case studies was to solicit suggestions for potential strategies that might be effective in reducing barriers and increasing AI/AN program enrollment. In particular, a comparative case study approach was designed and conducted to address several questions of interest for this study:

- What are the most significant barriers to AI/AN enrollment in each of the public insurance programs?
- How prevalent are the main barriers and how can they best be classified in a way that will help CMS and others to develop initiatives to address them?
- Do barriers differ in important ways by program? Are these differences due to programmatic idiosyncrasies, to differences in historical outreach to AI/ANs among the programs, or to differences in eligible populations (e.g., elderly versus working families)?
- How do barriers differ across Tribes and among urban, rural, and perimeter areas?
- Are some barriers to enrollment unique to AI/ANs and, as such, may require development of new, specifically targeted outreach strategies?
- Are there ways to reduce identified barriers to increase AI/AN enrollment in these programs? Which entities (Tribes, IHS, States, Federal government) might be best placed to initiate and carry out suggested strategies?

Across the 10 States, information from key informants was gathered in a highly structured method across multiple sites in each State through in-person and follow-up telephone interviews. The project team used the same discussion guide in each State to ensure that each State case study collected common information and that all important project research questions were addressed in the interviews. The individual State case studies were systematically constructed by summarizing each State's interview notes within a project team-developed descriptive framework to organize a case study; the team then identified program barriers and suggested strategies by classifying each into project team-standardized categories, for each State.

For each of the 10 States selected for the case study component of the project, site visits were conducted to:

- Two Tribes or AI/AN Reservations, to meet with Tribal leaders, Tribal health staff, IHS staff, and other local community members knowledgeable about program enrollment issues and processes (e.g., Title VI directors and Senior program directors).
- An Urban Indian Health Clinic.<sup>7</sup>
- State Medicaid, SCHIP, and other State Offices, such as State Health Insurance and Assistance Programs (SHIPs) and Elder Affairs Offices, with knowledge of AI/AN issues relevant to enrollment.

Additional appropriate organizations were interviewed when travel arrangements permitted and/or they were interviewed by follow-up telephone contacts (e.g., IHS Area Offices, Indian Health Boards representing multiple Tribes, CMS Regional Office staff, AI/AN referral hospitals, AI/AN epidemiology centers, and AI/AN elder housing facilities). For several site visits, County or State Medicaid and SCHIP eligibility workers were included in group interviews.

In total, more than 300 people participated in interviews conducted in the 10 States, including staff from State Medicaid, SCHIP, and Tribal liaison agencies, 22 Federally Recognized AI/AN Tribes or organizations, 9 Urban Indian Health Clinics, and 10 other organizations involved in AI/AN health and public program enrollment.

#### **KEY FINDINGS**

Interviewees identified a number of issues unique to AI/ANs that serve as barriers to enrollment in Medicaid, SCHIP, and Medicare. These include the relationship between the Federal government and Federally Recognized Tribes that may include Federal provision of health care and other services to members of these Tribes, and Tribal sovereignty issues that affects Federal-Tribal-State government-to-government relationships. The historical experiences of Tribes with Federal and State governments appear to have resulted in a degree of mistrust that affects the willingness of some AI/ANs to apply for enrollment in Federal- and State-sponsored health programs. Additionally, in many cases Tribal leaders and Tribal members perceive that the Federal Trust Responsibility to provide health care to the Tribes means that Tribal members should not need to apply for assistance through Medicaid, SCHIP, or Medicare. Many interviewees also stated that the fact that IHS services are available for routine primary and preventive care and some degree of specialty care for serious illnesses causes some AI/ANs to question the need to enroll in public programs. However, the IHS operates on an annual budget that has been set at levels that are insufficient to provide adequate services to meet the needs of the AI/AN population. Contract Health Services – services that cannot be provided and must be referred out to private providers - are particularly a problem for IHS- and Tribally managed health facilities to provide. The available funds for Contract Health Services is often depleted well before the end of the fiscal year and, as a result, AI/AN people may not receive these services at all or may face long delays in obtaining care unless their condition is immediately

<sup>&</sup>lt;sup>6</sup> While the goal was to visit two Tribes/Reservations per State, some variation existed among States. This variation was due either to unique circumstances in the State (e.g., Alaska's large geographic area and many small Native villages) or to recommendations from Technical Expert Panel members who felt that the study would benefit from extending the site visit to include several Tribes/Reservations in specific States.

<sup>&</sup>lt;sup>7</sup> North Dakota does not have an Urban Indian Health Clinic.

life-threatening. A number of interviewees suggested that Tribal leaders and Tribal members frequently are not aware of how increased public program enrollment might benefit the entire Tribe by providing additional third-party Medicare, Medicaid, and SCHIP revenues to IHS- and Tribally managed health facilities, thus making more services available to all Tribal members.

In addition to these barriers that are unique to AI/AN populations, other barriers were identified during interviews, including: lack of awareness about the existence of the programs (particularly SCHIP and the Medicare Savings Programs); limited knowledge of benefits and eligibility criteria for all of the programs; transportation barriers; language and literacy barriers; complexity of application and redetermination processes; and cultural barriers. Because a high proportion of AI/ANs resides in rural areas on Reservations with high poverty rates and low educational levels, these barriers may be significant deterrents to enrollment.

This study was not able to quantify the magnitude of the impact of specific barriers on enrollment rates. As a result, it is only possible to speculate which barriers are likely to have a significant impact on enrollment. The concentration of the AI/AN population in rural areas does suggest that transportation barriers may be substantial given long travel distances, lack of reliable personal transportation, limited access to public transportation to reach County or State eligibility offices, and the poor conditions of Reservation roads. In addition, outreach, education, and enrollment assistance has been found to be a much greater challenge in remote areas that require outreach/enrollment workers to travel long distances to reach clients and where televisions, radio stations, and newspapers are less available than in urban areas. The large number of different languages spoken by AI/ANs may also be a greater barrier to providing appropriate outreach and education. Many AI/AN languages are spoken languages only, requiring the use of non-written communication modes such as television, radio, and videotapes to effectively reach some people.

Strategies suggested by interviewees to reduce barriers to enrollment and to facilitate higher rates of AI/AN enrollment in Medicaid, SCHIP, and Medicare were strongly focused on increasing culturally-appropriate outreach and education materials and activities, and providing one-to-one assistance with application and redetermination processes. For the most part, these suggestions were coupled with interviewee recommendations that funding for outreach, education, and enrollment assistance activities be given directly to Tribes or to Urban Indian Health Clinics to design and implement such strategies.

A number of interviewees suggested that the Federal government provide funding to Tribes and Urban Indian Health Clinics to develop and implement locally-directed and AI/AN-specific outreach and enrollment assistance programs, either directly or through a requirement that States provide a share of Medicaid and SCHIP administrative match funds to Tribes and urban clinics. Some interviewees suggested that the Federal government establish a Tribal Medicaid option that would permit Tribes to manage their own Medicaid programs and determine eligibility for Tribal members. Several interviewees from Tribal, State, and Urban

Tribally managed facility, or Urban Indian Health Clinic).

<sup>&</sup>lt;sup>8</sup> A logical extension of this suggestion would be to extend the 100 percent Federal medical assistance percentage (FMAP) match to States for Medicaid services provided to eligible AI/ANs at Urban Indian Health Clinics. This option has been suggested by national AI/AN organizations, which would allow health care funds to "follow" an individual, irrespective of her location (on-Reservation or off-Reservation) and irrespective of provider (IHS facility,

Indian Health Clinics also suggested that developing processes to improve Federal-Tribal-State government-to-government relationships would be useful for reducing barriers and facilitating enrollment in these programs.

Many interviewees recommended that the States and/or Federal government provide improved training to Tribal, IHS, and Urban Indian Health Clinic staff on Medicaid, SCHIP, and Medicare benefits, eligibility requirements, and application processes as these are often the "front-line" staff that can best provide the one-to-one assistance needed. In addition, many interviewees suggested that simplifying the application process and making redetermination less frequent would be useful strategies. A number of interviewees also suggested that State/County eligibility workers – and Federal employees who work with Medicare, Social Security, and Social Security Disability Income application processes – be given more training on program and eligibility determination issues and on AI/AN history and legal issues that affect eligibility determination. Increased cultural awareness training for State/County eligibility workers was also suggested by some interviewees.

#### LIMITATIONS OF THE STUDY AND FEASIBILITY ISSUES

Limitations of this study may affect the validity of the findings and the extent to which they can be generalized to all AI/AN populations in the same or different States. These include:

- Individual interviewees expressed their views and perceptions, based on their own experiences and situations. The project team did not conduct an independent validation of these views and perceptions and, therefore, the interview findings may be based on inaccurate information and/or limited experiences that may not be generalizable.
- Information was obtained in only 10 States and, while these States have large AI/AN populations, the findings may not be generalizable to other States that may have different characteristics and AI/AN populations.
- Detailed information was obtained from only 22 Federally Recognized AI/AN entities or organizations across the 10 States, which does not encompass all Tribes in these States.<sup>9</sup>
   Thus, although the findings may reflect the characteristics and experiences of the Tribes/Reservations interviewed, they may not necessarily extend to other Tribes with different cultures, histories, and experiences that were not interviewed.
- At the time the site visits for this project were conducted, many States were experiencing budget shortfalls that were causing State governments to consider or institute cutbacks in Medicaid and SCHIP program benefits and/or outreach funds. The changes that were being contemplated may have affected the perceptions of Tribal and State interviewees about barriers to enrollment in these programs and strategies to increase AI/AN enrollment. The study findings might well be different if the site visits had been conducted during a period of economic expansion and State budget surpluses.

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<sup>&</sup>lt;sup>9</sup> Additional information was obtained from a larger number of Tribes through meetings with Indian Health Boards and input from TEP members and project consultants. This information, however, was more general and less detailed in nature than that obtained through visits or follow-up telephone interviews with individual Tribes.

However, the extensive number of individuals who participated in the interviews conducted in the 10 States (more than 300 individuals), and the comprehensive review process for the individual State case study reports undertaken for this project, suggest that this study can provide a basis for developing and testing strategies that may be successful in reducing barriers to AI/AN enrollment in Medicaid, SCHIP, and Medicare.

The specific strategies that have been suggested by participants in this study are wide-ranging, from relatively narrow, targeted strategies (e.g., provide more training on program eligibility criteria to State/County eligibility workers) to strategies that would require substantial changes in Federal and State policy (e.g., develop a Tribal Medicaid option). The feasibility of specific strategies has not been assessed in this study. However, it would be necessary to consider feasibility in considering and choosing specific strategies that might be implemented. The most important feasibility considerations are: 1) the cost of the strategy, if extended to all AI/AN populations; and 2) the political issues that would need to be addressed to implement the strategy.

With current Federal, State, and Tribal budget constraints, some strategies might require more resources relative to the benefits obtained than are considered reasonable. Similarly, strategies that would require Congress to act before they could be implemented and/or that would require negotiations between the Federal government, States, and Tribes (such as a Tribal Medicaid option) could take many years to develop and implement. These considerations should be assessed in order to determine whether the strategies identified in this study might be developed and implemented to reduce barriers and increase AI/AN enrollment in the Medicaid, SCHIP, and Medicare programs. Additionally, alternative ways to fund these strategies could be pursued. For example, CMS might consider using Department of Health and Human Services' education and outreach-targeted funds for reducing health care disparities among racial and ethnic minority populations to fund oral translation of educational materials into Native American languages, which are primarily spoken rather than written. Furthermore, ways to reduce strategy development and implementation costs could also be pursued. For example, CMS might consider using existing initiatives involving Tribal colleges and universities to help develop culturally-appropriate educational materials, at lower cost than might be obtainable through marketing firms.

# APPENDIX I.A: TECHNICAL EXPERT PANEL MEMBERS AND PROJECT CONSULTANTS

Technical Expert Panel (TEP) Members			
Name	Organization	State	
Jim Crouch	California Rural Indian Health Board	California	
Mim Dixon	Mim Dixon & Associates	Colorado	
Pamela Iron	National Indian Women's Health Resource Center	Oklahoma	
	Division of American Indian and Alaska Native Programs,		
Spero Manson	University of Colorado Health Sciences Center	Colorado	
Beverly Russell	National Council of Urban Indian Health	Washington, DC	
	National Association of State Medicaid Directors Tribal		
Nancy Weller	Work Group; Alaska Dept. of Health and Social Services	Alaska	
Laura Williams	Association of American Indian Physicians	California	
Jonathan Windy Boy	Montana/Wyoming Tribal Leaders Council	Montana	
	Native American Program Coordinator, Arizona Health Care		
Julia Ysaguirre	Cost Containment System/KidsCare	Arizona	

Project Consultants			
Name	Name Organization		
Rebecca Baca	Elder Voices	New Mexico	
	National Indian Project Center (formerly with the National		
David Baldridge	Indian Council on Aging)	New Mexico	
Ralph Forquera	Seattle Indian Health Board	Washington	
Carole Anne Heart	Aberdeen Area Tribal Chairmen's Health Board	South Dakota	
Jo Ann Kauffman	Kauffman & Associates	Washington	
Frank Ryan	I&M Technologies	Maryland	

# APPENDIX I.B: TRIBES, URBAN INDIAN HEALTH CLINICS, AND OTHER ORGANIZATIONS INTERVIEWED

#### Alaska

Alaska Native Health Board

Alaska Native Medical Center

Alaska Native Tribal Health Consortium

Alaska Native Tribal Health Directors

Denali Kid Care

Kasigluk Health Clinic

Southcentral Foundation

State of Alaska, Department of Administration, Division of Senior Services

State of Alaska, Division of Medical Assistance (Medicaid and SCHIP), State Federal and Tribal Relations

Yukon Delta Regional Hospital

Yukon-Kuskokwim Health Corporation

#### Arizona

Inter Tribal Council of Arizona

Navajo Area IHS (Area Office and Chinle, Fort Defiance, Kayenta, Tuba City, and Winslow Service Units)

Navajo Nation Division of Health

Navajo State Health Insurance Assistance Program

Phoenix Indian Medical Center

State of Arizona, Arizona Health Care Cost Containment System (AHCCCS)/KidsCare (Medicaid and SCHIP)

Tucson IHS Area (Area Office and San Xavier Health Center, Sells Hospital, and Pascua Yaqui Health Program)

Tucson Indian Center

#### Michigan

American Indian Health & Family Services of South East Michigan

Covering Michigan's Kids (Robert Wood Johnson Pilot Program)

Grand Traverse Band of Ottawa/Chippewa

Inter-Tribal Council of Michigan

Sault Ste. Marie Health & Human Services

State of Michigan, Department of Community Health (Medicaid and SCHIP)

#### **Minnesota**

Bemidji IHS Area Office Elder's Advocate, Leech Lake Elders Division Elders Lodge, St. Paul Fond du Lac Band of Ojibwe Great Lakes Inter-Tribal Epidemiological Center Hennepin County Medical Center Mille Lacs Band of Ojibwe Minneapolis Indian Health Board

Senior Linkage Line and Health Insurance Counseling, Metropolitan Area Agency on Aging State of Minnesota, Board on Aging Indian Elder Desk; Wisdom Steps Coordinator State of Minnesota, Department of Human Services (Medicaid and SCHIP)

#### Montana

Billings IHS Area Office
Chippewa-Cree Tribe of the Rocky Boy's Reservation
Crow Reservation
Fort Belknap Reservation
Great Falls Indian Family Health Clinic
Indian Health Board of Billings
Montana/Wyoming Tribal Leaders Council
State of Montana, CHIP Office (SCHIP)
State of Montana, Human and County Services Division (Medicaid)

#### North Dakota

Family Health Care Center
North Dakota Indian Affairs Commission
Northland Health Care Alliance
State of North Dakota, Department of Human Services (Medicaid)
State of North Dakota, Healthy Steps (SCHIP)
State of North Dakota, several County Social Services Directors
Trenton Indian Service Area
Turtle Mountain Reservation

#### **Oklahoma**

Cherokee Nation

Chickasaw Nation Carl Albert Indian Hospital

Choctaw Nation Health Service Authority

Citizen Potawatomi Nation Health Center

Covering Kids, Oklahoma (Robert Wood Johnson Pilot Program)

Indian Health Care Resource Center of Tulsa

Lawton Area Health Board

Lawton IHS Service Unit

Oklahoma Health Care Authority (Medicaid and SCHIP)

Tahlequah IHS Service Unit

#### **South Dakota**

Crow Creek Reservation

Native Women's Health Center

Rosebud Sioux Reservation

Sioux San Indian Health Service Hospital

South Dakota Urban Indian Health, Inc.

State of South Dakota, Department of Social Services (Medicaid and SCHIP)

State of South Dakota, Eligibility Office

#### **Utah**

Fort Duchesne IHS Service Unit

State of Utah, Department of Health (Medicaid and SCHIP)

Utah Indian Health Board

Utah Indian Walk-In Center

**Uintah-Ouray Reservation** 

#### Washington

CMS Regional Office X

Covering Washington's Kids (Robert Wood Johnson Pilot Program)

Lummi Nation

Seattle Indian Health Board

State of Washington, Department of Social and Health Services (Medicaid and SCHIP)

Yakama Nation

Yakama PHS Indian Health Center

#### APPENDIX I.C: INTERVIEW GUIDE

#### **Issues for Site Visit Interviews**

- 1. Are there AI/AN people here who are eligible for enrollment in Medicare, Medicaid, or SCHIP who are not enrolled?
  - a. Is under-enrollment in Medicare a serious problem?
  - b. Is under-enrollment in Medicaid a serious problem?
  - c. Is under-enrollment in SCHIP a serious problem?
  - d. Is under-enrollment of people who are QMBY/SLMBY-eligible a serious problem?
- 2. Do you think that most people who are eligible know about the programs?
- 3. What are reasons that people might not want to enroll in Medicare, Medicaid, or SCHIP?
- 4. Are there ways that information about the programs could be provided that would be more helpful to people who may be eligible?
- 5. Do you know people who have tried to enroll in Medicare, Medicaid, or SCHIP who have had problems? What types of problems do most people have?
- 6. Are there people who have difficulties with re-enrollment/verification processes? What types of problems do people have?
- 7. Are there any special programs or assistance here to help people enroll in Medicare, Medicaid, and SCHIP?
  - a. Outreach/education about the programs?
  - b. Help with paperwork for enrollment?
  - c. Legal assistance?
  - d. Transportation/child care assistance?
  - e. Benefits counselors or CHRs who help people enroll?
  - f. Other programs?
  - g. Who runs these programs?
- 8. How long have these programs or special assistance been operating? Do you think they've been effective in increasing enrollment?
- 9. Does your State help people to enroll in Medicaid or SCHIP?
- 10. What do you think should be done to help more people who are eligible to enroll in these programs?

#### CHAPTER II. ALASKA

#### **BACKGROUND**

#### Overview

This Case Study Report presents background information and findings based on a five-day site visit to Alaska conducted from August 19 to August 23, 2002. The site visit team included Kathryn Langwell and Tom Dunn from Project HOPE and Frank Ryan, J.D., project consultant. Linda Greenberg, Ph.D., CMS Project Officer, also participated in this first site visit conducted for the CMS study of American Indian/Alaska Native (AI/AN) Eligibility and Enrollment in Medicaid, SCHIP, and Medicare. The team visited Anchorage, Bethel, and Kasigluk, Alaska, and conducted interviews with individuals and groups in each location, as well as met with the Alaska Native Tribal Health Directors and the Alaska Native Health Board. A list of individuals with whom the site visit team met, and members of the Alaska Native Tribal Health Directors and the Alaska Native Health Board is presented in Appendix II.A. An earlier draft of this Case Study was sent to CMS for review and comments received were incorporated into the Draft Case Study. This second version of the Draft Case Study was then sent to key contacts in Alaska with a request for their review and comments. Response to this request was received only from the State contact and the comments provided were incorporated into this Final Case Study.

The comments and recommended strategies contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or the feasibility of the recommendations made by the interviewees. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services (CMS), the Indian Health Service (IHS), Tribes and Tribal organizations, or the State.

#### Alaska AI/AN Population and Location

The State of Alaska has a population of 635,000 people, of whom 98,000 (15 percent) are Alaska Native or American Indian. The Alaska population was 70.4 percent urban in 1999 with a population density of 1.1 persons per square mile. Anchorage is the largest city in the State with a population of over 260,000; there are only six communities in the State with over 30,000 population. Over one-half of the AI/AN population resides in rural areas (i.e., towns, villages, or clustered settlements). 11

Major industries in Alaska include mining, oil and gas production, fishing and seafood processing, and transportation. Nearly 10 percent of the population has incomes at or below the Federal Poverty Level.

10 U.S. Census Bureau: State and County Quick Facts, http://quickfacts.census.gov/qfd/States/02000.html.

Alaska Population Overview, 1999 Estimates, Department of Workforce Development (ISSN 1063-3790), http://www.labor.State.ak.us/research/pop/chap1.pdf.

The majority of the Alaska Native population lives in small remote villages of less than 1,000 people and which are sufficiently isolated that access to health care services requires long travel times. Over 80 percent of villages are inaccessible by road and transportation to health care facilities relies on air, boat, or snowmobile. The lack of roads and the cost of air transport between villages and urban centers with health facilities pose significant barriers to use of health services.

Over 54 percent of Alaska Natives have incomes below the Federal Poverty Level or are unemployed. <sup>12</sup> Those who live in remote villages rely on subsistence activities (i.e., hunting, fishing, food gathering) for survival. Employment opportunities are generally seasonal, rather than year round. Because of the high rates of poverty, a substantial proportion of Alaska Natives are eligible for Medicaid and Denali KidCare (Alaska's SCHIP program). However, there are lower than average rates of Medicare eligibility, particularly in remote villages, due to the lack of opportunities for regular employment and contributions to Social Security during prime working years that are less than the 40 quarters requirement.

#### AI/AN Health Services in Alaska

Alaska Natives administer 99 percent of IHS funds in Alaska under compacts, contracts, and grants. There are six Alaska Native-managed hospitals located in rural communities and 24 health centers. Alaska Native communities without a hospital or health center are served by 176 community health aide clinics. The Alaska Native Medical Center in Anchorage serves as a referral center for specialty and tertiary care.

The coordination and collaboration among Alaska Native groups to manage Statewide health services for all Alaska Natives is unique. The Alaska Native Tribal Health Consortium (ANTHC), owned by health corporations, represent all 229 Tribes in the State. Together with the Southcentral Foundation (which provides primary and specialty services to Alaska Natives in the Anchorage area), the ANTHC operates the Alaska Native Medical Center that serves all Alaska Native people in the State.

#### **Alaska State Medicaid and SCHIP Programs**

The Division of Medical Assistance administers the Alaska Medicaid and SCHIP programs. In 2002, the income eligibility standard for children, pregnant women, and families with children was 200 percent of the Alaska-adjusted Federal Poverty Level (FPL);<sup>13</sup> that is, annual income for a family of four must not exceed \$44,140.<sup>14</sup> Medical assistance is also provided to individuals receiving Supplemental Security Income (SSI) who have incomes below the 74<sup>th</sup> percentile of the Alaska-adjusted FPL. The State of Alaska's SCHIP program, Denali KidCare, is a Medicaid expansion program. Eligibility for Denali KidCare is set at 200 percent of the adjusted FPL for uninsured children and at 150 percent of the FPL for insured children.

<sup>&</sup>lt;sup>12</sup> Bureau of Indian Affairs estimates, 2001.

<sup>&</sup>lt;sup>13</sup> Due to the high cost of living in Alaska, the Federal Poverty Level is 25 percent higher than the level in the lower 48 States.

<sup>&</sup>lt;sup>14</sup> http://www.hss.State.ak.us/dma/DenaliKidCare/gen info.htm, accessed May 29, 2003.

About 40 percent of over 60,000 people enrolled in the Alaska Medical Assistance Program is Alaska Native or American Indian. Approximately 8,500 people were dually enrolled in Medicare and Alaska Medical Assistance. The Yukon-Kuskokwim Health Corporation data on Medicaid enrollment rates in 48 villages it serves ranged from a low of 11 percent to a high of 94 percent, with an average of 40 percent across all the villages.

High proportions of AI/AN children who are not enrolled in Medicaid qualify for and are enrolled in Denali KidCare. There has been extensive outreach and efforts to enroll children in Denali KidCare through The Robert Wood Johnson Foundation Covering Kids program, the Department of Health and Social Services, and Alaska Native health facilities.

There appears to be a very strong and positive working relationship between the State Division of Medical Assistance (DMA) and the Alaska Native Health Corporations. The DMA provides outreach services, encourages enrollment of AI/ANs into Medicaid and Denali KidCare, has provided technical assistance to improve third-party billing capabilities, and works closely with the Corporations to resolve billing errors rather than denying claims.

There is variation, however, among Alaska Native Health Corporations and health facilities in the sophistication of their information systems and capabilities for third-party billing and collections and in their effectiveness in using these systems. The intensity of interest in outreach and enrollment assistance to Tribal members may be affected by the extent to which financial benefits may accrue from investing in these activities.

#### **FINDINGS**

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Despite the relatively high enrollment rates of Alaska Natives in Medicaid and SCHIP, there was consensus across all interviewees that under-enrollment remains a major issue in all areas of the State. A very high proportion of the Alaska Native population is very poor and, even though many are enrolled in Medicaid and SCHIP, most interviewees said that they believed that considerably more AI/ANs are eligible and not enrolled. These individuals indicated that IHS funding to the Alaska Native Health Corporations is inadequate to meet the health care needs of the population, particularly for specialty and tertiary care. In addition, funds to pay transportation costs are very limited and, in general, health facilities provide transportation services only for life or limb threatening cases. A major incentive for individuals to enroll in Medicaid or Denali KidCare is that these programs pay transportation costs for enrollees. Barriers to enrollment fall into two categories: 1) barriers to initial enrollment; and 2) barriers to maintaining enrollment.

#### Barriers to Initial Enrollment

- Some AI/AN's believe that the Federal government's trust responsibility to provide health care to the AI/AN population means that it is not necessary or appropriate for them to seek other forms of government-paid health coverage.
- The paper work associated with applying for Medicaid is difficult for many to complete without extensive assistance. Some people are unwilling to reveal personal and financial information to eligibility workers who could help with paperwork.

- There is a lack of outreach and enrollment assistance in some areas of Alaska. In remote areas, it is difficult for outreach and enrollment assistance to be provided regularly although some Health Corporations make more effort than others to do so. More enrollment workers are needed, but funds are not available to pay them. Transportation costs and inclement weather that affects the ability to travel by outreach and enrollment workers also limit the availability of assistance in more remote areas.
- Long travel distances, transportation costs, and harsh weather conditions also are a barrier to individual AI/ANs who might consider initiating enrollment, particularly in areas where outreach and enrollment workers do not reside in or frequently visit villages.
- Enrollment assistance is very time-consuming at the local level since enrollment workers must spend time in the community to gain acceptance and trust. Cultural protocol also requires that enrollment workers "connect" with people by identifying common relatives and understanding of local customs.
- When an application to Denali KidCare is denied, those interviewed consistently stated that it is unlikely that the applicant will appeal the decision even if the denial was due to a request for additional information or clarification.
- Language barriers to understanding written and oral information about programs are an issue, particularly in smaller and more remote villages. There are over 30 Native languages but materials are only provided in English. In addition, limited literacy of a portion of the population that speaks English makes completion of the application forms difficult. Many of the native Alaskan languages are spoken and not written. Due to the complex nature of the enrollment issues being discussed, communication in these languages is, therefore, a very time-consuming process.
- "Word of mouth" about the administrative requirements (e.g., prior authorization) and rules that must be observed under Medicaid to obtain approved services deters some people from applying.

#### **Barriers to Maintaining Enrollment**

- Seasonal patterns of employment result in some people losing coverage because for a few months of the year monthly income may exceed eligibility standards for Medicaid and Denali KidCare. For those who are members of some Alaska Native Corporations and receive annual dividends, this once-a-year payment also may affect eligibility.
- The pattern of seasonal re-location to pursue subsistence activities (i.e., hunting, fishing) may result in failure to receive mail notification of requests for redetermination of income and eligibility.
- Language and literacy barriers result in a failure to understand written requests for redetermination of income and eligibility. Failure to respond to the redetermination request results in termination of enrollment in Medicaid and Denali KidCare.

- The State does not share information with Health Corporations and health facilities about Medicaid and Denali KidCare enrollees who are asked for redetermination information, so assistance in responding to the request cannot be provided unless the individual seeks help.
- Once an individual is terminated from the program, for whatever reason, he or she tends to believe he/she is no longer eligible and is reluctant to initiate a new enrollment application.

#### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

While the general perception of interviewees is that there are some AI/ANs who are eligible for Medicare but not enrolled, much less concern was expressed about this underenrollment than for Medicaid and Denali KidCare. This was due, according to those interviewed, to the relatively small proportion of aged people in the AI/AN population. In addition, several interviewees at different sites stated that there was less incentive to make an effort to enroll people in Medicare because they believed Medicare reimbursement is low relative to Medicaid and Denali KidCare and the rules and regulations that must be complied with to receive reimbursement are difficult and costly. Whether these perceptions are correct or not, the fact that a number of Alaska interviewees repeated them suggests that this belief may be widespread and may affect the extent to which efforts are made to increase Medicare enrollment for those who are eligible.

Other barriers to enrollment in Medicare faced by those who are eligible and not enrolled were suggested by interviewees and include:

- The paperwork required by the Social Security Administration to obtain Supplemental Security Disability Income (SSDI) is very complicated. Most applicants are reportedly turned down at least once, and the process requires determination and ongoing persistence. There is little assistance available to help with the process and a tendency among Alaska Native people to accept the initial rejection as final. Family members or enrollment workers who call the Medicare or Social Security offices to obtain information to assist Medicare or Social Security applicants are told that this information will only be provided directly to the applicant, unless a power of attorney is filed with the agency on its approved form. While the State's State Health Insurance and Assistance (SHIP) office is available to assist beneficiaries with their questions/problems, some elderly Alaska Natives may face language barriers, travel barriers, and/or may lack telephone services that would enable them to make use of SHIP services or to contact Medicare and Social Security offices on their own.
- There are a significant number of AI/AN Medicare beneficiaries who are not enrolled in Part B because it requires a \$54 a month premium. For those who are very poor or who lead a subsistence lifestyle, the premium is a substantial barrier to enrollment in Part B. If they later decide that they should enroll in Part B, the higher cost to "buy-in" is often more than they can afford. During the site visit, there was little evidence to confirm that the Medicare Savings Programs (QMB, SLMB, etc.) were promoted with the same effort as Medicaid and Denali KidCare, even though such programs may have been helpful.

- Many elderly believe that they must pay co-payments that are required under Medicare, even though they are exempt from co-payments when they receive services through Tribally managed health facilities. "Word of mouth" about co-payment requirements persuades some that Medicare will cost them money if they join.
- Outreach and enrollment assistance for Alaska Natives who are eligible for Medicare and Medicare Savings Programs is more limited than for Medicaid or Denali KidCare eligibles. The Alaska SHIP provides free health insurance counseling and assistance to people in Medicare, and conducts outreach primarily via printed material in English. Outreach staff only conducts visits to communities of 1,000 populations or more. While the SHIP establishes partnerships with health facilities, social service agencies, and other organizations to get the "word" out, the focus of most Tribal health facilities is on Medicaid and Denali KidCare enrollment activities.
- Outreach and enrollment workers at Tribal health facilities do not have the training or knowledge of the Social Security, SSDI, and Medicare application processes that would help them to provide assistance with the paperwork and processes that are required to obtain Medicare coverage.

#### Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

Tribal health facilities and the State Department of Health and Social Services (DHSS) conduct most outreach and enrollment into Medicaid and Denali KidCare. Some health facilities have developed extensive programs to enroll as many eligible people as possible. Examples include:

Alaska Native Medical Center (ANMC). The ANMC has a Family Health Resources (FHR) department with 10 employees responsible for identifying eligible-but-notenrolled patients and helping them apply for Medicaid, Denali KidCare, or Medicare. FHR receives referrals from social service agencies and other organizations and has "walk-ins" who ask for assistance with applications. Each day, FHR also receives a printed inpatient roster. Patients who do not indicate a third-party payer are identified and an FHR staff person visits those patients to discuss their potential eligibility for Medicaid, Denali KidCare, or Medicare. 15 If the FHR staff person determines that the patient may be eligible, then enrollment assistance is provided. The FHR has developed a good working relationship with the Anchorage Social Security office and with the State public assistance office and expedited enrollment can be arranged. FHR staff will even accompany the patient to the appropriate office to facilitate the process if needed. Despite these efforts, FHR estimates that 46 percent of patients have no other source of insurance. Typically, of eight people who enter the hospital with no other insurance, FHR estimates that only three are eligible for Medicaid, Denali KidCare, or Medicare. These enrollment assistance programs at ANMC do have one major limitation – the ANMC does not

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<sup>&</sup>lt;sup>15</sup> Patients who are admitted for more serious (i.e., potentially expensive) conditions are given highest priority for FHR screening and assistance.

provide follow-up once the applicant returns home after initiating the application for Medicaid <sup>16</sup>

• Yukon-Kuskokwim Health Corporation (YKHC). YKHC benefits/enrollment staff provides outreach and assistance both to patients at the health center and in the nearly 50 villages that YKHC serves. A two-person outreach and enrollment team visits each village for one or two days once every three months, with advance publicity, and assists people with paperwork and follow-up. The team also goes "door-to-door" while in the village, talking to people about Medicaid and Denali KidCare and encouraging them to apply. YKHC also tracks eligibility redetermination and enrollment staff also contact those who are expected to receive redetermination materials to offer assistance with completing and returning the forms. YKHC encourages people to apply for and enroll in Medicaid or Denali KidCare through a policy that limits payment for transportation services in an area that requires long travel for many people to obtain health services.

The DMA also undertakes a number of activities to encourage enrollment in its programs, with a strong emphasis on Denali KidCare. There is very active marketing of Denali KidCare throughout the State through billboards, printed materials, traveling health fairs, and "gifts" (e.g., a packet for children including a button, toothbrush, and a small first-aid kit with contact numbers for enrollment). Other steps that DMA has taken to encourage and maintain enrollment include:

- Single parents are not required to provide information about the absent parent for Denali KidCare enrollment. DMA identified the requirement for information about absent parents as a significant deterrent to enrollment.
- Denali KidCare redetermination materials are sent out every six months, with all previous eligibility determination data filled in for the applicant. If nothing has changed, the applicant has merely to sign and mail back the form with proof of current income.
- The State trains "fee agents" on the application process and the information required to fill out forms. These agents are present in most communities and villages and are available to assist people to apply for Medicaid and Denali KidCare. The fee agent is paid \$35 by the State for every application that he or she assists to complete and submit, whether the applicant is determined to be eligible or not.
- DMA has developed an agreement with Tribal Health Corporations through which DMA will provide a 50 percent match of Tribal costs for outreach, enrollment, training, and travel costs for enrollment activities serving Alaska Natives.<sup>17</sup>

Individuals interviewed during the site visit provided the following suggestions to increase enrollment rates and reduce attrition from programs:

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<sup>&</sup>lt;sup>16</sup> The State staff notes that the lack of follow-up is due to the fact that the patients come from all over the State and there is no way to assist long distance once they return home.

<sup>&</sup>lt;sup>17</sup> State staff that reviewed this case study Stated that the administrative match is now in place, with several corporations taking advantage of assistance with Medicaid outreach and enrollment.

- Educate community members. Greater efforts should be made by Tribal Health Corporations and health facilities to educate community members about the benefits to themselves and to everyone in the community of enrolling in Medicaid, Denali KidCare, and Medicare. Tribal health is inadequately funded and services can be expanded only if the additional revenues from third-party payers are available.
- Funding for outreach and enrollment workers. CMS, the Social Security Administration, and the State should make funding for additional outreach and enrollment workers, and for travel costs associated with outreach and enrollment assistance at the community level, available to Tribal Health Corporations.
- Clarify denial letters. Letters of denial of eligibility, from all agencies, should clearly State the reason for denial. If the denial is due to missing information, it should not say "denial" but instead should request additional information and indicate that this is part of the ongoing process of determining eligibility. 19
- Account for seasonal income. Income eligibility requirements for Medicaid and Denali KidCare should take into account and adjust for seasonal income that causes monthly income levels to exceed eligibility requirements for only a few months a year.
- **State notification of redetermination.** The State should notify Tribal Health Corporations or facilities when Medicaid or Denali KidCare enrollees are to be recertified or that an application has been denied, so that Tribal enrollment counselors can contact the enrollee/applicant to assist with the paperwork.<sup>20</sup>
- Clarify Explanation of Medicare Benefits form. For services provided to a Medicare beneficiary through a Tribal health facility, the Explanation of Medicare Benefits sent by CMS to the Medicare beneficiary should be modified to indicate that co-payments are not the responsibility of the individual.
- **Develop training program.** A training program on Social Security and Medicare eligibility and application procedures should be developed and made available to Tribal outreach and enrollment workers.
- **Develop improved financial and billing systems.** Financial and/or technical assistance should be provided to Tribal Health Corporations (by IHS, CMS, or private foundations) to develop more sophisticated financial and billing systems to equip them to meet

<sup>19</sup> The Alaska Medical Assistance Program notifies clients who have submitted applications with missing information that their application is pended for a set time period because additional information is needed. If the missing information is not provided within that time period, the application is denied.

<sup>&</sup>lt;sup>18</sup> Evidence cited by interviewees included reference to the Indian Health Service Level of Need Funding study, which estimated that IHS receives only 50-60 percent of the funding necessary to provide a full range of services to its AI/AN patients. In addition, all Tribal health facilities visited indicated that they exhausted their Contract Health Services budgets several months before the end of each fiscal year and had to deny services (except for life-threatening illnesses) until the next fiscal year began.

<sup>&</sup>lt;sup>20</sup>Under Federal rules, the State is not permitted to share information about the status of eligibility of any client, unless the client requests that it does so or the facility is the client's authorized representative. In addition, HIPAA regulations that will be implemented in October 2003 may make it more difficult to implement this suggestion.

requirements for Medicare providers and to be efficient and effective in billing for third-party reimbursement. The capability and potential to increase revenues through Medicare, Medicaid, and SCHIP would provide greater incentives to conduct more aggressive outreach and enrollment assistance.

### APPENDIX II.A: ALASKA SITE VISIT CONTACTS

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### CHAPTER III. ARIZONA

#### **BACKGROUND**

#### Overview

This Draft Case Study Report presents background information and findings from a five-day site visit to Arizona conducted from October 28 through November 1, 2002. The site visit team consisted of Mary Laschober (Site Coordinator) and Erika Melman of BearingPoint, and Rebecca Baca of Elder Voices, project consultant. The team visited the Navajo Reservation, Tucson Indian Health Service (IHS) Area staff and American Indian/Alaska Native (AI/AN) Tribes located in the Tucson area, the Tucson urban Indian health clinic, and the Inter Tribal Council of Arizona in Phoenix. Following the site visit, the team held telephone interviews with the Native American Coordinator for Arizona's Medicaid Office, the Navajo Area Agency on Aging, and the Phoenix Indian Medical Center. The rationale for selecting the sites visited and description of the sites is provided in the following section. This section describes the AI/AN population and AI/AN health services in Arizona, as well as Arizona's Medicaid program and its State Children Health Insurance Program (SCHIP) and governing agencies.

The CMS Project Officer and other CMS staff reviewed an earlier version of this Case Study Report for accuracy and clarity. Subsequently, a revised Draft Case Study Report was sent to each of the Arizona organizations that participated in the site visit, with a request that the draft be reviewed for accuracy and to incorporate comments and additions into the final Case Study Report. Follow-up telephone contacts were made with all of the above-mentioned organizations. Comments and corrections were received from Tucson Area IHS staff and Tucson area Tribal representatives and the Native American Coordinator for the AHCCCS/KidsCare programs.<sup>21</sup>

The comments and recommendations contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or the feasibility of the recommendations. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services (CMS), the Indian Health Service, or the State.

### Arizona AI/AN Population and Location

AI/ANs living in Arizona are much less healthy in many ways compared with the overall Arizona population. Some telling 2002 comparative statistics include the following:<sup>22</sup>

 Average age at death from all causes: All Arizonans = 71.2 years; Arizona AI/ANs = 54.3 years

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<sup>&</sup>lt;sup>21</sup> Comments on the Arizona case study report were solicited from the Navajo Nation Division of Health and the Navajo Area IHS Office but were not received by the end of the project contract and, therefore, are not included in the report.

<sup>&</sup>lt;sup>22</sup> AI/AN is self-reported on vital statistics forms. Source: Mrela, C.K., Assistant Registrar of Vital Statistics and Coe, T., Senior Research Data Analyst. *Health Status Profile of American Indians in Arizona: 2001 Data Book.* January 2003.

- Incidence of low birth-weight births (per 100 births): All Arizonans = 7.0; Arizona AI/ANs = 7.3
- Incidence of pregnancy-associated hypertension in mother (per 1,000 births): All Arizonans = 26.3; Arizona AI/ANs = 57.1
- Incidence of gestational diabetes (per 1,000 births): All Arizonans = 22.2; Arizona AI/ANs = 61.8

AI/AN populations in the three Arizona IHS Areas compare less favorably than the average IHS Area AI/AN population and the overall U.S. population with respect to education, unemployment, poverty rates, and births to diabetic mothers (Table 1). However, the Arizona IHS Area populations are generally comparable to the average IHS Area AI/AN population with respect to low and high weight birth rates and life expectancy at birth. Although the top three leading causes of death for the Arizona IHS Areas are the same as for the average IHS AI/AN and the overall U.S. populations, accidents and adverse event death rates are higher for the former group. Also, similar to the average IHS Area AI/AN population, Arizona AI/ANs have higher death rates from diabetes than the overall U.S. population.

Table 1. Selected Demographic and Health Statistics, Arizona IHS Areas, All IHS Areas, and U.S.-All Races

Statistic	Navajo IHS Area	Phoenix IHS Area	Tucson IHS Area	All IHS Areas	U.S., All Races
Percent High School Graduate or Higher, 1990	54.8	59.4	52.1	65.3	75.2
Percent of Males Unemployed, 1990	23.5	21.0	25.2	16.2	6.4
Percent of Females Unemployed, 1999	18.6	17.4	20.2	13.4	6.2
Percent of Population Below Poverty Level, 1990	46.8	41.8	24.0	31.6	13.1
Low Weight Births (Percent of Total Births), CY 1996- 1998	6.3	6.7	7.3	6.3	7.5*
High Weight Births (Percent of Total Births), CY 1996- 1998	8.2	11.0	10.0	12.6	10.2*
Birth Rates with Diabetic Mother (Rates per 1,000 Live Births), CY 1996-1998	65.0	62.5	54.2	48.3	26.4*
Leading Causes of Death, CY 1996-1998 (Percent of Total Deaths)					
Diseases of the Heart	16.2	17.4	17.0	21.6	31.4*
Malignant Neoplasms	12.4	10.7	10.7	15.9	23.3*
Accidents & Adverse	21.8	18.8	15.0	14.0	4.1*
Effects					
Diabetes Mellitus	5.6	8.5	8.4	6.6	***
Chronic Liver Disease &	***	6.8	9.2	4.5	***
Cirrhosis					
Cerebral Vascular Diseases	***	***	***	***	6.9
Pneumonia & Influenza	5.9	***	***	***	***
Life Expectancy at Birth, Males, CY 1996-1998**	68.0	66.4	61.6	67.4	73.6*
Life Expectancy at Birth, Females, CY 1996-1998**	76.5	72.0	70.7	74.2	79.4*

Source: Demographic and Dental Statistics Section of Regional Differences in Indian Health 2000-2001: Charts Only, Statistics Program, Indian Health Service, Department of Health and Human Services, July 2002. \* CY 1997.

#### AI/AN Health Services in Arizona

Three IHS Area Offices serve the State of Arizona: The Phoenix Area IHS Office, the Tucson Area IHS Office, and the Navajo Area IHS Office. The Phoenix Area IHS Office in Phoenix, Arizona, oversees the delivery of health care to approximately 105,000 AI/ANs in the States of Arizona, Nevada, and Utah – from the small Cocopah Tribe in southwestern Arizona to the widely dispersed Paiute Indians in Nevada and Utah. The Phoenix Area Office operates primarily as an administrative center for 10 Service Units, which may include one or more health centers or hospitals. More than 40 Tribal groups reside within the Phoenix Area IHS region varying in size, locale, and affiliation.

Nine IHS hospitals operate within the Phoenix Area, the largest of which is the Phoenix Indian Medical Center. Patients are referred there for specialized care that is not available at the eight Reservation hospitals. IHS also operates seven health centers and six health stations. A

<sup>\*\*</sup> Adjusted for race miscoding.

<sup>\*\*\*</sup>Not a leading cause of death.

growing number of health facilities throughout the Phoenix Area are Tribally operated. As of January 1990, AI/AN Tribes operated four of these health centers and two of these health stations. Service Units in Schurz, Nevada, and Fort Duchesne, Utah, operate both clinics and health centers. Some clinics are staffed by one or more IHS personnel who are stationed in the local community. In addition, local physicians and dentists are often under contract to the IHS. Traveling teams of IHS medical and allied health professionals serve other areas.<sup>23</sup>

Situated in south-central Arizona and extending south to the U.S./Mexico border, the Tucson Area IHS Office service area encompasses two Service Units that serve the Pascua Yaqui and Tohono O'odham Reservations, the latter being the second largest in the United States with almost three million acres. Health care in the Sells Service Unit is a combined effort of IHS and the Tohono O'odham Health Department, providing a comprehensive health program of inpatient services, ambulatory care, and community health services. Health services for the Tohono O'odham Tribe are centered in Sells, Arizona, capital of the Tohono O'odham Reservation. Sells lies 60 miles east of Tucson, Arizona's second largest metropolitan area.

Sells Indian Hospital, a modern 37-bed facility with JCAHO accreditation, is the central component of the Sells Service Unit, providing general medical and primary care on an inpatient and outpatient basis. Some emergency services are provided, although most critical-care patients are transferred to one of several Tucson or Phoenix area private or IHS hospitals. Hospital admissions total approximately 1,200 patients annually, including 50 to 100 obstetrical deliveries. Another 200 to 300 deliveries are performed through contracts with Tucson facilities. Exclusive of dental visits, ambulatory visits number approximately 20,000 per year. Health centers are also located in the Reservation communities of Santa Rosa and San Xavier. The San Xavier Health Center is a large outpatient facility on the outskirts of Tucson, and the Santa Rosa Clinic is a small outpatient facility located in the very rural setting of the north-central sector of the Tohono O'odham Reservation.

The Tucson Area IHS and the Pascua Yaqui Tribe jointly manage the Yaqui Service Unit. Services are rendered directly and indirectly through a non-traditional, innovative system of subcontracts, including some services through a Tucson-based health maintenance organization. Both the Sells and Yaqui Service Units are administered by the Office of Health Program Research & Development, an IHS headquarters component located at San Xavier. <sup>24</sup>

The Navajo Area IHS Office, located in Window Rock, Arizona, administers numerous clinics, health centers, and hospitals, providing health care to 201,583 members of the Navajo Nation through eight Service Units. The Navajo Nation is the largest Indian Tribe in the United States and has the largest Reservation. The Reservation encompasses more than 25,516 square miles in northern Arizona, western New Mexico, and southern Utah, with three satellite communities in central New Mexico. The Navajo Area Office coordinates with both the Phoenix and Albuquerque Area IHS Offices for the delivery of health services to the Navajo, Hopi, and Zuni Reservations because these Reservations are close to each other.

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<sup>&</sup>lt;sup>23</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Phoenix/Phoenix.asp, accessed June 18, 2003.

<sup>&</sup>lt;sup>24</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Tucson/tucsonsu-facilities.asp, accessed June 18, 2003.

Comprehensive health care is targeted to the Navajo people through inpatient, outpatient, contract, and community health programs centered around 6 hospitals, 7 health centers, and 12 health stations. School clinics and Navajo Tribal health programs also serve Reservation communities. The six hospitals range in size from 39 beds in Crownpoint, New Mexico, to 112 beds at the Gallup Indian Medical Center in Gallup, New Mexico. Health centers operate full-time clinics, some of which provide emergency services. Some smaller communities have health stations that operate only part-time.

A major portion of the Navajo Nation health care delivery system is sponsored by the Navajo Tribe itself, which operates the Navajo Division of Health (NDOH) in Window Rock, Arizona. The NDOH, created in 1977, has the mission of ensuring that quality and culturally acceptable health care is available and accessible to the Navajo people through coordination, regulation, and where necessary, direct service delivery. The NDOH provides a variety of health-related services in the areas of nutrition, aging, substance abuse, community health representatives (e.g., outreach), and emergency medical services (e.g., ambulance). The Division provides services for infants, children, youth, adults, elders and their families throughout the various communities within and adjacent to the Navajo Nation. These are administered by the Executive Administration, the Department of Program Operations, the Department of Health Services, the Navajo Area Agency on Aging, and the Department of Behavioral Health Services<sup>25</sup>

# Overview of Arizona State Government<sup>26</sup>

The Arizona Commission of Indian Affairs (ACIA) was formed in 1953 to "consider and study conditions among the Indians residing within the State." In 1986, the Arizona legislature gave ACIA a new mission to be the State's liaison with the 21 Federally Recognized Indian Tribes in Arizona. State leaders intended that ACIA's work would help foster enhanced Tribal-State communication, leading to better relationships between the Tribes and State agencies. The ACIA, which meets quarterly, consists of the governor, the superintendent of public instruction, the director of the department of health services, the director of the department of transportation, the attorney general, the director of the department of economic security, the director of the office of tourism, the director of the department of commerce, and nine members appointed by the governor, two at large who are non-Indian and seven from among Arizona's Indian Tribes.

ACIA's legislatively mandated activities include assembling facts needed by Tribal, State, and Federal agencies to work together effectively; assisting the State in its responsibilities to Tribes by making recommendations to the Governor and Legislature; conferring and coordinating with other governmental entities and legislative committees regarding AI/AN needs and goals; working for a greater understanding and improved relationships between AI/ANs and non-AI/ANs by creating an awareness of the needs of AI/ANs in the State; promoting increased participation by AI/ANs in State and local affairs; and helping Tribal groups develop increasingly effective methods of self-government.

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<sup>&</sup>lt;sup>25</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Navajo/gimc/Nav.asp, accessed June 18, 2003.

<sup>&</sup>lt;sup>26</sup> http://www.indianaffairs.State.az.us, accessed 6/18/03.

# Arizona State Medicaid Program<sup>27</sup>

Arizona's Medicaid program, the Arizona Health Care Cost Containment System (AHCCCS), administers an array of health care programs. AHCCCS has operated under a CMS 1115 Research and Demonstration Waiver since 1982, being the first Statewide Medicaid managed care system in the United States. AHCCCS contracts with public and private health plans and other program contractors (for long-term care benefits), paying them a monthly "capitation" amount prospectively for each enrolled member. The plan or contractor is then "at risk" to deliver the necessary services within the capitated amount. AHCCCS receives Federal, State, and County funds to operate, plus some monies from Arizona's tobacco tax and tobacco settlement funds. In contrast to the acute care and long-term care program, behavioral health services are carved-out and delivered through an Intergovernmental Agreement between AHCCCS and the Arizona Department of Health Services (ADHS). ADHS contracts with Regional Behavioral Health Authorities to deliver behavioral health services to members.

AHCCCS eligibility is not performed under one roof, but by various agencies, depending on the category. For example, most Arizona residents generally enter AHCCCS by way of the State Department of Economic Security (DES). Prior to October 1, 2001 and passage of Arizona Proposition 204, Arizona's 15 counties were responsible for determining individuals' eligibility for most AHCCCS programs. Blind, aged or disabled persons who receive Supplemental Security Income (SSI) enter through the Social Security Administration (SSA). Eligibility for categories such as KidsCare (Arizona's SCHIP program), SSI-related groups, long-term care, women diagnosed with breast or cervical cancer, and Medicare Cost Sharing programs (Arizona's name for the Medicare Savings Programs<sup>28</sup>) is handled by AHCCCS itself. Each eligibility group has its own income and resource criteria. As of October 1, 2002, AHCCCS covers the following groups of people under the Medicaid Program (a more detailed description of several of these programs follows):

- Families and children under Section 1931 of the Social Security Act.
- Single adults and childless couples under the 100 percent Federal Poverty Level (FPL) Waiver.
- Individuals or families who incur sufficient medical expenses that when deducted from income will reduce income to 40 % of the FPL.
- Pregnant women at or below 140 percent FPL.
- Children under age 1 whose income is at or below 140 percent FPL.

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http://www.ohca.State.ok.us/, accessed April 4, 2003.

The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

- Children age 1 thru 5 whose income is at or below 133 percent FPL.
- Children age 6 thru 18 whose income is at or below 100 percent FPL.
- Individuals who are aged, blind, or disabled with income at or below 100 percent FPL who meet the SSI requirements.
- Persons under age 21, who were in foster care on their 18<sup>th</sup> birthday.
- Persons who meet one of the categorical linked Medicaid programs except for citizenship or qualified immigrant status (emergency services only).
- Persons eligible for the Medicare Cost Sharing Programs (i.e., "Medicare Savings Programs" as they are referred to at the Federal level). and
- Women under age 65, diagnosed as needing treatment for breast or cervical cancer.

AHCCCS for Families with Children (AFC) provides medical coverage, such as doctor's office visits, hospitalization, prescriptions, lab work, and behavioral health services to families (parents of qualifying children are covered). To qualify, there must be a child in the household under the age of 18 years (or 19 years if a full-time student). The monthly income limit for this program is 100 percent of FPL. There is no limit on the resources or property that may be owned.

AHCCCS Care provides medical coverage, such as doctor's office visits, hospitalization, prescriptions, lab work, and behavioral health services for adults with no qualifying children for the AFC program. The monthly income limit for this program is 100 percent of FPL. There is no limit on the resources or property that may be owned.

SOBRA provides medical coverage to pregnant women and children up to the age of 19 years. For pregnant women, the monthly income limit is 133 percent of FPL; for children under the age of 1, the monthly income limit is 140 percent of FPL; for children ages one through six, the monthly income limit is 133 percent of FPL; for children age six and older, the monthly income limit is 100 percent of FPL. There is no limit on the resources or property that may be owned.

The Medical Expense Deduction (MED) program provides medical coverage for individuals who do not qualify for other AHCCCS programs because their income is too high. However, they may be eligible for MED if they have medical expenses in the month of application (or the previous month) that reduce their monthly income to 40 percent of FPL. Resources cannot exceed \$100,000, and only \$5,000 may be liquid assets, such as cash, bank accounts, stocks, bonds, etc. Home equity is counted toward the resource limit, but one vehicle is not counted.

Medicare Savings Programs in Arizona have the same income eligibility limits as all other States; however, there is no limit on resources, such as cash, bank accounts, stocks, or

bonds in Arizona. Applicants for all programs must be eligible for Medicare Part A. Individuals may apply for this program by mail.<sup>29</sup>

Health care services are provided through AHCCCS health plans. All eligible children have a choice of available contractors and primary care providers in their geographic service area. All AHCCCS medical services are authorized and coordinated through the AHCCCS health plan. Health plans contract with community clinics, doctors, pharmacies, hospitals and laboratories to provide services. There are at least two health plans in each County. AI/ANs can elect to receive services through IHS or Tribal health facilities instead of an AHCCCS health plan. If an AI/AN selects the IHS or a Tribal facility, AHCCCS provides any services not provided by these entities on a fee-for-service basis off-Reservation. Except for AI/AN recipients, AHCCCS enrollees may change their health plan annually upon notification by AHCCCS of the annual enrollment period, or if they move and the health plan is not available at their new residence. AI/AN recipients may change from a health plan to an IHS/Tribal facility or back to a health plan at any time upon request. AI/ANs residing in a Reservation Zip Code area are defaulted into an IHS/Tribal facility if they do not actively choose a health plan; those living outside of a Reservation Zip Code are defaulted into an AHCCCS health plan.

A joint seven-page (excluding instructions) AHCCCS/KidsCare application, available in English and Spanish, is used to apply for the above programs. To participate in these programs, all individuals must be U.S. citizens or qualified immigrants. Arizona residents can use one simple form to apply for AHCCCS health insurance for themselves and everyone in their immediate family who lives with them. The application can be downloaded from Arizona's website, obtained by calling a Statewide toll free number, and is available at DES offices and many other community organizations in the State. A completed application can be mailed; most programs do not need a face-to-face interview if AHCCCS can contact applicants by phone.

Applications and enrollment information are also available at IHS and appropriate Tribal locations. AHCCCS also uses Native American events, newspapers, and radio stations as a forum for outreach. If IHS or Tribal staff is willing to assist applicants in completing the application for AHCCCS health insurance, AHCCCS provides training. AHCCCS has a Native American Coordinator who is available to the Tribes for consultation, information and presentations.<sup>31</sup>

Co-payments are assessed for both AHCCCS and KidsCare programs in the amounts of \$1 for each physician visit, laboratory and x-ray procedure; \$5 for non-emergency surgery; and \$5 for non-emergency use of the emergency room, but are waived for AI/AN recipients.

In addition to the above AHCCCS programs, Arizona offers the Premium Sharing Program (PSP), funded solely with State dollars, that provides medical coverage for uninsured

<sup>&</sup>lt;sup>29</sup> http://www.ahcccs.State.az.us/services/Overview/ForArizonans.asp#MCS, accessed May 16, 2003

<sup>&</sup>lt;sup>30</sup> Based on the demographics in Arizona of other ethnic groups, AHCCCS does not believe that developing the application in other languages is necessary since no other ethnic group exceeds 3% of the population. However, an interpreter is provided, if needed, http://www.ahcccs.State.az.us/publications/Kidscare/kidscare\_2002/Section%204.pdf, accessed May 18, 2003.

<sup>&</sup>lt;sup>31</sup> http://www.ahcccs.State.az.us/publications/Kidscare/kidscare 2002/Section%204.pdf, accessed May 18, 2003.

individuals who have not been covered by health insurance for at lease one month, unless the loss of health insurance was involuntary. PSP offers insurance coverage to low income individuals with income above the Medicaid guidelines if they pay modest co-payments (ranging from \$5 to \$50) and monthly premiums. Monthly household income cannot exceed 200 percent of FPL. However, if the individual is chronically ill, monthly household income limits cannot exceed 400 percent of FPL. Premiums are based on income and the number of eligible household members, and can be up to 6 percent of gross income for those with incomes up to 200 percent of FPL. Those with incomes from 200 to 400 percent of FPL must pay the full premium. PSP has limited enrollment; as of May 16, 2003, PSP is not accepting applications except for a limited number of chronically ill applicants.

# **Arizona SCHIP Program**

In May 1998, the Arizona legislature authorized the implementation of a stand-alone Title XXI State Child Health Insurance Program, referred to as Arizona KidsCare. Arizona's income threshold for this program is set at 200 percent of FPL, with no asset test required.<sup>32</sup>

KidsCare provides the same services, for the same co-payments, offered to AHCCCS recipients for children under 19 years old who have had no employer-provided or privately purchased health insurance within the past three months. The latter exclusion, however, does not apply to AI/ANs receiving services from an IHS or Tribally operated facility. An eligible child must live in Arizona, be a United States citizen or an eligible qualified immigrant, be ineligible for health insurance coverage as an employee of the State of Arizona or family member of a State of Arizona employee, be ineligible for Medicaid, and not reside in a public institution or an institution for mental disease.<sup>33</sup> Applicants are required to provide proof of immigrant status for children who are immigrants and proof of all household income.

The joint AHCCCS/KidsCare application is used to determine whether a child is eligible for AHCCCS prior to a determination of eligibility for KidsCare. An individual may apply for KidsCare by mail, telephone, or on-line. No DES office visit or interview is required. A child who is determined eligible for KidsCare is guaranteed an initial 12 months of continuous coverage (except in particular circumstances, such as attainment of age 19 or attainment of employer-sponsored health insurance).

Health care services are provided through established AHCCCS health plans, with KidsCare recipients having the same options as AHCCCS eligibles. Like AHCCCS recipients, AI/ANs can elect to receive services through IHS or Tribal health facilities instead of a KidsCare health plan. If an AI/AN selects the IHS or a Tribal facility, AHCCCS pays for any off-Reservation KidsCare services not provided by these entities on a fee-for-service basis. KidsCare enrollees may change their health plan annually upon notification by AHCCCS of the annual enrollment period, or if they move and the health plan is not available at their new residence. AI/AN enrollees may change from a health plan to an IHS/Tribal facility or back to a health plan at any time upon request to the State.

<sup>32</sup> http://www.kidscare.State.az.us/English/Kids\_HealthPlans.asp, accessed May 16, 2003.

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<sup>33</sup> http://www.ahcccs.State.az.us/publications/Kidscare/kidscare\_2002/Section%204.pdf, accessed June 18, 2003.

On January 1, 2003, coverage was extended to parents of AHCCCS and KidsCare children with family income between 100 and 200 percent of FPL, using SCHIP funds. As the second phase of Arizona's Health Insurance Flexibility and Accountability (HIFA) initiative, this expansion followed the November 1, 2001 HIFA expansion to childless adults with income up to 100 percent of FPL (also using SCHIP funds). Childless adults had originally been part of the broader expansion subsequent to the passage of Arizona Proposition 204, the Healthy Arizona Initiative, which was implemented beginning April 1, 2001 and provided coverage of a number of groups up to 100 percent of FPL using Medicaid funds.<sup>34</sup>

On October 1, 1999, KidsCare implemented premiums for families with an income above 150 percent of FPL. For monthly household incomes up to 150 percent of FPL, there is no monthly premium. For monthly household incomes from 150 percent to 200 percent of FPL, a monthly premium is charged, ranging from \$10 to \$15 a month for one child or \$15 to \$20 a month for two or more children. AI/ANs are not required, however, to pay premiums or copayments.

### **DESCRIPTION OF SITE VISIT**

### Overview

Prior to conducting the site visit from October 28 through November 1, 2002, the team contacted Julia Ysaguirre (AHCCCS Native American Program Coordinator), Technical Expert Panel (TEP) member; Rebecca Baca (Elder Voices), Project Consultant; Mary Lou Stanton, Charlotte Melcher, and Barney Ahgoon from the Phoenix IHS Area Office; and Anslem Roanhorse from the Navajo Area IHS Office. Rebecca Baca, in turn, held several discussions about site visit options, coordination, and required research protocols with Navajo Nation Tribal leadership (particularly Robert Nakai, Interim Director of the Department of Navajo Health who also represented Vice President McKenzie of the Navajo Nation), and with Taylor Satala, director of the Tucson Area IHS office and former Service Unit Director of the Keams Canyon Service Unit, as well as chairman of a national workgroup for the Inter Tribal Council of Arizona.

The team solicited advice from these contacts as to which communities the site visit team should visit in Arizona, who initial key contacts might be, and which issues specific to the State should be addressed in the study. According to the Case Study Design Report approved by CMS, the team solicited input on one Tribal area with Tribally managed health facilities, one Tribal area with IHS-operated facilities, and one urban area with an Urban Indian Health Center that delivers medical services. The team also stressed that travel distances were an important consideration in recommending sites. The purpose of the site visit was to meet with approximately 10 to 12 key organizations/people per State. The team also tried to schedule inperson discussions with State Medicaid and SCHIP staff and IHS Area Office staff.

Based on advice, travel considerations, and responses from Arizona organizations as to their desire to participate in the study, the team selected Navajo Nation and Tucson IHS Area

 $<sup>^{34}</sup>$  http://www.gao.State.az.us/financials/CAFR/CAFR2002/02-%20CAFRall.pdf, accessed 6/18/03, and CMS comments from July 10, 2003.

Tribes for the Tribally-based site visits, the Tucson Indian Center for the urban area site visit, and the Inter Tribal Council of Arizona (ITCA) in Phoenix. We also did follow up calls with the Phoenix Indian Medical Center and the State Medicaid Office located in Phoenix.

The Tucson Indian Center recently received an IHS contract to provide AI/AN health services in Tucson. The ITCA is an advocacy agency funded by all Arizona Tribes except for Navajo and governed by a board of Tribally elected leaders. ITCA administers many programs for Arizona Tribes, including several funded through the Arizona Area Agency for Aging programs, WIC, Elder Outreach Services, the Tribal Epidemiological Center, and tobacco education monies earmarked for Arizona Tribes. The Tucson IHS Area Tribes encompass both IHS- and Tribally-administered health care facilities. In addition, the Tucson IHS includes the Tohono O'odham Nation, which resides on the second largest Reservation in the United States and is unique because its lands cut through Mexico, perhaps creating difficulties for Medicaid access for foreign-born AI/ANs.

Navajo Nation possesses many qualities that made it an interesting choice for a site visit. It is a vast and rural Reservation, with its own Area Agency on Aging, IHS Area Office, and Bureau of Indian Affairs Area Office. Navajo Nation has a strong culture and language. Moreover, Navajo Tribal members feel that their numbers are not truly reflected in IHS statistics.

Like the Tucson IHS Area Tribes, Navajo Nation encompasses both IHS- and Tribally-administered health care facilities. Until recently, all health facilities were IHS-directed, but Navajo Nation recently contracted with the IHS to operate two facilities (Winslow and Tuba City) in the eight Navajo IHS Area Service Units to become "638" contract providers in the fall of 2002. As such, we were able to hear about the challenges that health facilities face when transitioning to Tribal management.

As previously mentioned, the Navajo Reservation overlaps three States (Arizona, New Mexico, and Utah), and health facilities serve patients from those three States as well as a fourth State (Colorado). All of these States have different processes and procedures for their respective public insurance programs, which creates unique barriers and policy issues for the Navajo people and the health facilities that serve them. For example, New Mexico implemented an expanded Medicaid program for its SCHIP program, which means it receives a 100 percent match for IHS services provided to AI/ANs. In contrast, Arizona implemented a stand-alone SCHIP program and does not receive the 100 percent match.

It was also suggested that we conduct a "regional" site visit and not restrict the visit to Arizona areas of Navajo Nation; however, the project's budget did not allow for this. Because the Navajo Reservation and Navajo IHS Area cover three different States, because it is the largest Reservation in the United States, and because the Navajo IHS Area consists of eight IHS Service Units, IHS and Navajo Nation contacts strongly recommended that we extend the time we were to spend on Navajo Reservation to at least three days (normally, the site visit team spends one day at each site). With CMS approval, the site visit team spent three days on the part of the Navajo Nation Reservation located in Arizona, one day was spent interviewing organizations in the Phoenix IHS Area, and one day consisted of interviews with organizations in the Tucson IHS Area.

Navajo IHS staff also with determining whether the site visit team needed to participate in the Navajo Nation's Institutional Review Board (IRB) process. Subsequent to site visit team and CMS Project Officer discussions with Navajo Nation leadership and staff from the Navajo Division of Health, we were informed that we would not need to complete the IRB process to hold key informant interviews on the Navajo Reservation for this study.

The site visit team relied heavily on local Tribal and Urban Indian Health Center key contacts to determine which groups and individuals the team should speak with and at which places and times, in accordance with the Case Study Design Report. The team provided a list of potential interviewees to an identified key contact at each interview site. The list included Tribal leaders, Tribal health directors and Tribal health board members, IHS service unit directors, Contract Health Services directors, community health representatives/community health aides, Title VI directors/elder organization leaders, IHS hospital and clinic staff including alternative resource specialists, case managers, billing specialists, and patient benefits coordinators and counselors, urban Indian center and clinic staff, and other organizations that serve the AI/AN community (e.g., Area Agencies on Aging, out-stationed or County Medicaid/SCHIP eligibility workers, Indian alcohol treatment centers, Indian education programs, and Tribal or County social services agencies). The individuals and organizations with which the site visit team met in Arizona or conducted follow-up telephone interviews are listed in Appendix III.A.

# **Description of Navajo Nation**<sup>35</sup>

The Navajo Nation Reservation extends into the States of Arizona, New Mexico and Utah, covering over 27,000 square miles, including all or parts of 13 counties in those States. According to the 2000 U.S. Census, 298,197 individuals claimed Navajo ethnicity. As of November 30, 2001 (according to Navajo Nation Vital Records Office), 255,543 of these individuals are enrolled members of the Navajo Nation. Not all Navajos live on Tribal land: according to the 2000 U.S. Census, 168,000 Navajo enrolled members reside on Navajo Nation Tribal land and 12,000 non-members reside and work within the Navajo Nation. Another 80,000 Navajos reside near or within "border towns" of the Navajo Nation. The remaining Navajos, enrolled and non-enrolled, reside in metropolitan centers across the United States. The Navajo Nation population is relatively young with a median age of 22.5 years.

The Navajo Nation government is composed of three branches – executive, legislative and judicial – and is centrally headquartered in Window Rock, Arizona. It is comprised of an elected Tribal president, vice-president and 88 council delegates representing 110 local units of government (known as Chapters) throughout the Navajo Nation. Council delegates meet a minimum of four times a year as a full body in Window Rock. The 110 Chapters are the local form of government and each chapter elects a chairman, vice chairman, secretary/treasurer, and other officials. Community meetings are held in the Chapter houses.

For decades, the Navajo Nation government has been supported by revenue from natural mineral resources. However, realizing that natural resources will not last forever, other alternatives to pay for services for Tribal members are being explored. In addition, in 1984 the

<sup>&</sup>lt;sup>35</sup> Information in this section was obtained at http://www.nnwo.org/nnprofile.htm, accessed June 19,.2003, unless otherwise noted.

Navajo Nation Council established a Permanent Trust Fund, into which 12 percent of all revenues received each year are deposited. Under Navajo law, however, the trust fund cannot be used until the year 2004.36

Despite its revenue from natural resources, according to the 2000/2001 Comprehensive Economic Development Strategy report from the Navajo Nation Division of Economic Development, 56.1 percent of Navajo people live below the poverty level, the per capita income is \$6,217, and the unemployment rate is 43.7 percent. The Navajo Nation is challenged daily by the tasks associated with attracting businesses to a business environment that has little or no infrastructure. On a regular basis, businesses explore the possibility of locating to the Navajo Nation before realizing the obstacles of inadequate paved roads and lack of electricity, water, telecommunication, and police and fire protection services. According to the Navajo Department of Transportation, 78 percent of the Reservation's approximately 9,286 miles of public roads are dirt or graveled. According to the Census 2000 report from the Division of Economic Development, Navajo Nation, of the 68,744 housing units on the Navajo Nation, 15,279 homes, or 31.9 percent, lack complete plumbing; 13,447 homes, or 28.1 percent, lack a complete kitchen facility; and 28,740 homes, or 60.1 percent, lack telephone service.

### **Description of Tucson Area Tribes**

The IHS in Tucson works with the Tohono O'odham Nation (formerly known as the Papago), and the Pascua Yaqui Tribe of Arizona. As of December 2000, the population was reported at nearly 24,000 people.<sup>37</sup> The Tohono O'odham Nation consists of four smaller Papago Indian Reservations. The Tohono O'odham Reservation stretches 90 miles across the Sonoran desert along the southern boundary of Arizona, extending into northern Mexico. To the north of Tohono O'odham is the smaller Gila Bend Reservation, to the east is San Xavier Reservation (just south of the city of Tucson), and east of the Gila Bend Reservation is the much smaller (20 acre) Florence Village. The location of the Tohono O'odham Nation allows easy access from Tucson and many other southern Arizona destinations. Sells, Arizona, is the Nation's capital. This area has been the ancestral homeland of the Tohono O'odham Nation for more than 2,000 years.38

The Tohono O'odham Nation is comparable in size to the State of Connecticut. Its four non-contiguous segments total more than 2.8 million acres. Within its land, the Nation has established an industrial park near Tucson and operates three casinos.<sup>39</sup>

The Tohono O'odham Tribal members have one of the highest occurrences of Type II diabetes in the world. Diabetes prevention projects are in place in the schools and community as a collaborative effort of IHS and the Tohono O'odham Health Department. The programs, including several rural field units, are geared toward educating Tribal members in methods of coping with and preventing the disease. 40

<sup>&</sup>lt;sup>36</sup> http://www.sos.State.nm.us/BLUEBOOK/navajo.htm, accessed June 19, 2003.

<sup>&</sup>lt;sup>37</sup> http://www.itcaonline.com/Tribes/tohono.htm, accessed June 21, 2003.

<sup>&</sup>lt;sup>38</sup> http://www.noao.edu/outreach/kptour/kpno tohono.html, accessed June 21, 2003.

<sup>&</sup>lt;sup>39</sup> http://www.itcaonline.com/Tribes/tohono.htm, accessed June 21, 2003.

<sup>&</sup>lt;sup>40</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Tucson/tucsonsu-facilities.asp, accessed June 18, 2003.

Not Federally Recognized until 1994, the Pascua Yaqui Indians have faced a long battle for the benefits of Tribal status. The Tribe is descended from ancient Uto-Aztecan people. The Pascua Yaqui originally inhabited the length of the Rio Yaqui River in southern Sonora, Mexico. They formed concentrated settlements, or rancherias, and practiced farming and hunting. After the Mexican War of Independence from Spain in 1821, the Yaqui resisted the Mexican government and gradually began to migrate north into Arizona. By 1919, only three original Yaqui rancherias remained. The best known Arizona Yaqui village is Old Pascua in the heart of what is now the City of Tucson. With Tribal recognition and acquisition of Reservation land just west of the San Xavier District in 1978, the village of New Pascua was built and remains the seat of Yaqui Tribal government. The Pascua Yaqui Indian Reservation, consisting of 892 acres, is located 15 miles southwest of Tucson.

An estimated 3,058 people lived on the Reservation in 1999. The estimated unemployment rate in that year was 23.8 percent. The Tribal government is the largest employer on the Reservation. The Tribe operates a landscape nursery business and manufactures adobe blocks. The Tribe also opened a 9,000 square foot bingo hall in 1992, which was expanded in 1994 to include a casino. The Casino of the Sun opened in 1994 and The Casino Del Sol opened in 2001. All gaming facilities are located southwest of Tucson.

# **Description of Arizona Urban Areas**

### **Tucson Indian Center**

The Tucson Indian Center primarily serves the urban AI/AN population of Pima County, Arizona. Tucson is ranked eighth in the United States in terms of urban AI/AN population. According to the 2000 U.S. Census, 15,358 persons who identify themselves as AI/AN alone or in combination with another race/ethnicity live in Tucson.<sup>45</sup>

The Tucson Indian Center provides a number of services including job training for clients eligible for Job Training and Partnership Act (JTPA) funds, employment and vocational counseling and referrals, emergency assistance with payment of bills and provision of food, and referrals to other resources. The Center also provides counseling, prevention, and early intervention activities for youth and adults at risk of drug and gang involvement. The Center recently became the IHS Urban Indian Health Center contractor for AI/ANs living in the Tucson urban area, administering the IHS contract for preventive services and case management and referral services. Although at this time it does not provide clinical services, interviewees noted that the Center is seeking funds to provide more direct health care services. Additionally, although Center staff said they do not currently have a public benefits outreach program, it has discussed developing one to fold into their existing community-based education activities.

<sup>&</sup>lt;sup>41</sup> http://www.carizona.com/nativeland/yaqui.html, accessed June 22, 2003.

<sup>42</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Tucson/tucsonsu-pascua-yaqui.asp, accessed June 22, 2003.

<sup>43</sup> http://www.commerce.State.az.us/pdf/commasst/comm/pas-yaq.pdf, accessed June 22, 2003.

<sup>44</sup> http://www.itcaonline.com/Tribes/pascua.htm, accessed June 22, 2003.

<sup>&</sup>lt;sup>45</sup> Forquera, R. *Urban Indian Health*. Prepared by The Seattle Indian Health Board for The Henry J. Kaiser Family Foundation, November 2001.

<sup>46</sup> http://www.uihi.org/uihp/Tucson/area demo.asp, accessed Mayu 19, 2003.

# Phoenix Indian Medical Center<sup>47</sup>

The Phoenix Area Indian Health Service (PAIHS) Office in Phoenix, Arizona, oversees the delivery of health care to approximately 140,000 Native American users in the tri-State area of Arizona, Nevada and Utah. Located primarily to the northeast and south of Phoenix are the communities and Reservations of the Mojave-Apache, Pima-Maricopa, Yavapai-Apache, Tonto Apache, and the Yavapai-Prescott Tribes served by the Phoenix Service Unit of the PAIHS. Much more urbanized than in other Service Units, each of these Tribes is autonomous and publishes its own community newspaper. The Phoenix Indian Medical Center (PIMC), located in the Phoenix Unit, is the largest of the nine PAIHS hospitals in the Phoenix area. Patients are referred here for specialized care not available at Reservation hospitals. PIMC is a JCAHO-accredited 163-bed hospital that employs nearly 600 people to provide its comprehensive range of specialty services.

In addition, PIMC provides inpatient and outpatient care through Contract Health Services to AI/ANs in the more remote sections of the Phoenix Service Unit. The PIMC professional staff also travels throughout the States in the PAIHS, providing consultation and guidance to other IHS hospitals and health centers. The Medical Center offers residency programs in surgery and OB-GYN, as well as various student-training programs. An entire floor of PIMC is devoted to research conducted by the National Institutes of Health on selected diseases of high prevalence among southwestern Tribes.

# The Inter Tribal Council of Arizona (ITCA)

The ITCA was established in 1952 to provide a united voice for Tribal governments located in Arizona and to address common issues and concerns. In 1975, the council established a private, non-profit corporation to promote Indian self-reliance through public policy development. Tribal chairpersons, presidents, and governors represent the 20 member Tribes of ITCA. A Board of Directors governs ITCA and a staff of 50 and other consultants, overseen by an Executive Director, carries out its work. ITCA operates more than 20 projects to provide ongoing technical assistance and training to Tribal governments in program planning and development, research and data collection, resource development, management and evaluation. The staff of ITCA also organizes and conducts seminars, workshops, conferences and public hearings to facilitate participation of Tribal leaders in the formulation of public policy.

The ITCA initiatives include environmental and natural resources program, health programs, and human services programs. Health programs provided through ITCA include the Community Tobacco Education and Prevention Project; Tribal Health Steering Committee for the Phoenix Area IHS; the Regional STD/HIV/AIDS Prevention Project; Nutrition Services for Diabetes Program; Childhood Obesity Prevention Program; WIC Program; American Indian Research Center for Health; Dental Support Center; and the Regional Tribal Epidemiological Center established in cooperation with the IHS. The ITCA is also a Phoenix Area Agency on Aging (AAA) grantee, with funding for AAA projects funded through the Federal Administration on Aging, CMS, and the IHS. The ITCA AAA subcontracts with Tribal

<sup>&</sup>lt;sup>47</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Phoenix/PxPxSU.asp, accessed May 19, 2003.

<sup>48</sup> http://www.itcaonline.com/mission.html, accessed 5/19/03.

governments to provide the following services across the State: adult daycare, benefits outreach, case management, congregate meals, home adaptation and renovation, home delivered meals, home health and personal care, information and referral, long term care advocacy for those off Reservation, ombudsman services, outreach, respite care services, transportation services, socialization and recreation, training and technical assistance for home and community-based services.

### FINDINGS: ARIZONA MEDICAID AND OTHER STATEWIDE AGENCIES

# **Arizona Health Care Cost Containment System (AHCCCS)**

### **Overview**

Following the site visit, we conducted a telephone interview with the Native American Coordinator for the AHCCCS/KidsCare programs. She has occupied the position for five years under the Office of Policy, which is responsible for inter-governmental relations. The Office of Policy staff works mainly with Tribal councils, but staff also works at the community level with clinics and providers. The staff's responsibilities include training IHS and Tribal health personnel about basic eligibility requirements for AHCCCS and other information regarding application and access to services. According to the Native American Coordinator, the State has funded out-stationed Department of Economic Security (DES) eligibility workers in almost all hospitals in the State (IHS, Tribal, and non-AI/AN hospitals).

# Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

According to the Native American Coordinator, AI/AN enrollment in AHCCCS is not a serious problem Statewide, characterizing it as more of a "moderate" problem. She believes the primary barriers are consumer lack of understanding about 1) the benefits of the different programs, 2) how Medicare, AHCCCS, and KidsCare services coordinate with IHS/Tribal health services, and 3) available options for program recipients to receive care from IHS/Tribal health facilities. The overriding barrier is that many AI/ANs are unaware of how to use health insurance or access health services outside of IHS/Tribal health care systems because they do not receive enough information about these issues.

Additionally, the Native American Coordinator said that AI/AN under-enrollment in KidsCare is a larger problem than for AHCCCS programs because many Tribal members do not understand the eligibility requirements or benefits of the KidsCare, so they "default" to the IHS or Tribal system with which they are familiar. For example, she noted that many Tribal members have always obtained outpatient prescription drugs from IHS. Now that Tribal members are increasingly required to go outside of that system to obtain their prescriptions – particularly for newer drugs that the IHS may not provide – they do not know where to go or how to pay for the drugs. Another example is that some AI/ANs carry a KidsCare or AHCCCS insurance card, but do not know what it is for (e.g., Arizona pays out-of-State providers, but an AI/AN consumer that the Native American Coordinator spoke with did not know that she was supposed to present her Arizona Medicaid card to a Utah Medicaid provider). Some do not show their Medicaid card

for fear they will be turned away from an in- or out-of-State provider who does not accept Medicaid.

Other barriers the Native American Coordinator discussed include:

- AI/AN lack of awareness that they can use IHS as their primary care provider under the AHCCCS managed care program;
- Some AI/ANs (e.g., non-pregnant adults) are not exempt from Medicaid cost-sharing for non-IHS/Tribal providers with some services requiring a \$1 co-payment;
- Lack of transportation to DES offices to enroll despite DES eligibility offices being located on the larger Arizona Reservations (e.g., there are several DES offices on the Navajo Reservation).

The Native American Coordinator does not believe that posters are a good strategy for reaching AI/ANs, who generally require in-person outreach. She said, for example, that KidsCare outreach has been slow among AI/ANs because the State no longer has resources to do one-to-one outreach. The State used to fund "outreach contractors," which she believes made some inroads into increasing AHCCCS and KidsCare enrollment among AI/ANs. These positions are no longer funded because of State budget shortfalls.

# Barriers to Maintaining Enrollment

The Native American Coordinator believes that annual redetermination is a greater problem with the KidsCare program than AHCCCS. She said that most people who receive AHCCCS also receive food stamps and State cash assistance, which they apply for simultaneously in person. In contrast, KidsCare is a "stand-alone" program for most recipients with redetermination accomplished primarily through the mail. Some AI/ANs, however, do not pay attention to their renewal notice. She said that Patient Benefit Coordinators (PBCs) at several IHS and Tribal facilities have started to inform patients to bring their redetermination package to PBCs for assistance. Besides this solution, however, the Native American Coordinator stated that she is "lost for ideas on how to better address this problem."

### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Until a couple of years ago, the Native American Coordinator said that AI/AN underenrollment in the Medicare Savings Programs was a serious problem but would characterize it as a moderate problem currently. She mainly attributes the turn-around to ITCA's AAA program's success in conducting public assistance outreach to AI/AN Tribes in Arizona through a Federal grant. She could not think of any reasons AI/ANs would not want to enroll in the Medicare Savings Programs.

The Native American Coordinator estimated that a "sizeable number" of AI/ANs in Arizona do not qualify for Medicare Part A due to insufficient work history, as well as there being many AI/AN widows who do not realize they are eligible under their spouse's work history. Additionally, she said there are a relatively small number of former Bureau of Indian

Affairs employees (mainly men) whose income was not reported to the Social Security Administration and, therefore, do not appear to have met the work requirements for automatically receiving Medicare Part A benefits.

# Strategies to Increase Enrollment in Medicaid and SCHIP

The Native American Coordinator reported that she does some application assistance and training for community- and Tribally-based organizations, but that recent cutbacks in the State's budget limits training to requests only, when resources are available. Prior to budget cutbacks, AHCCCS had an on-site regular training schedule and provided outreach grants that included training. Currently, IHS organizes annual training conferences in Arizona that AHCCCS staff attends (e.g., at annual IHS Patient Registration Conferences, Billing Conferences). Additionally, the interviewee regularly attends the AAA Elder Conference to share program information.

The Native American Coordinator suggested several strategies to increase AI/AN enrollment in AHCCCS and KidsCare:

- Improve consumer education about KidsCare program benefits and how AI/ANs would benefit from enrollment. She believes consumer education is best done through community education efforts with money provided directly to Tribes for this purpose. Successful community education efforts also require that Tribal leaders "buy-in" to the program and conduct any promotion directly.
- One-to-one consumer education and assistance, and additional IHS funding or funding from third-party revenues for additional PBC hires. The Native American Coordinator suggested that PBCs are in the best position to provide one-to-one consumer education and assistance (which the Coordinator believes is the best strategy for increasing AI/AN enrollment), as they are generally very knowledgeable about AHCCCS and KidsCare programs. Additionally, she believes that most PBCs have established local DES contacts from which they can obtain information and assistance. She said most PBCs already provide application assistance.
- Use Community Health Representatives (CHRs) to conduct outreach. The Coordinator believes that most CHRs are in a good position to educate consumers and provide one-to-one application assistance because they are often invited into people's homes. However, she cautioned that CHRs are often already inundated with work. She suggested they could be a good resource if the program could be expanded to include increased funding for more CHRs who could be reimbursed for application assistance and outreach. At present, AHCCCS can only reimburse them for providing transportation assistance to help AHCCCS or KidsCare recipients access program services.
- Provide additional program training for PBCs, CHRs, and other health and social services providers.
- Provide direct funds to ITCA to become a clearinghouse for program information. The Coordinator believes this would be a good strategy for providing PBCs with needed information easily and quickly. She suggested that information provided through a

website would be helpful, but because many PBCs and others do not have access to the Internet, other information access modes would also be necessary.

#### Other Issues

The Native American Coordinator noted that HIPAA will require IHS and Tribal facilities to transition to detailed billing systems. The AHCCCS claims office is currently updating its AI/AN health claims manual to reflect this change.

# **Navajo Nation State Health Insurance Assistance Program (SHIP)**

### Overview

Arizona's Region 7 Agency on Aging (AAA) is divided into five agencies that provide direct services to elders, as well as information and referral, finance, law, care management, home care, senior housing, health care, and social services counseling services. The AAA also provides Medicare insurance counseling through the State Health Insurance and Assistance Program (SHIP). Under a Tri-State Agreement with Arizona, New Mexico, and Utah, the Navajo Nation AAA provides these services to Navajo Nation elders within all areas of the Navajo Reservation. The Navajo Nation SHIP is not funded directly through CMS SHIP funds; it receives funding from the Arizona and New Mexico SHIPs but none yet from the Utah SHIP.

Subsequent to our site visit, the site visit team conducted a telephone interview with the director of the Navajo Nation SHIP. He said he believes that their SHIP works very well with the New Mexico and Arizona SHIP offices, but is just starting to work with the Utah SHIP.

### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

The interviewee estimated that most eligible Navajo Nation elders are enrolled in Part A but generally do not understand how the program works. He also said that most Navajo Nation AI/AN elders do not pay the Medicare Part B premium because they cannot afford it and because they do not understand why they might need this coverage. Similar to the AHCCCS Native American Coordinator, the SHIP interviewee noted that many elders do not understand how the Medicare and Medicaid programs interact with the IHS/Tribal health system. They generally do not understand how to use any non-IHS or health insurance/health care system. He said they are "scared of it because they feel it's too complicated," and some have been told "their (Medicare or Medicaid) card is no good." Because of their lack of understanding, they often believe that the services they need are not covered and can be easily intimidated by the "wrong words."

In attempting to educate AI/ANs about the Medicare Savings Programs, the interviewee said Navajo Nation SHIP staff have found that some elders, although aware of the programs, "stubbornly refuse to apply" because they believe the Federal government has a trust responsibility to provide them with health care without their having to apply for it. Additionally, he said the application is difficult for many elders and that DES offices sometimes do not even understand the Medicare Savings Programs and cannot relay the benefits and application requirements correctly to potential eligibles. He knows that PBCs at some IHS facilities will

send Medicare Savings Programs applications home with clients but do not have the time to provide application assistance so the applications are not completed.

The SHIP interviewee also emphasized that the difficulty of translating English terms into Navajo (e.g., there is no Navajo word for Medicare) can be a serious obstacle to application. Additionally, he said that Medicaid is very confusing to Navajo Nation elders due to differences in programs among the three States (e.g., he said that New Mexico Medicaid does not pay for services in Arizona or Utah).

The SHIP interviewee, however, believes that "baby boomers" retiring in two to five years will be much more aware of the Medicare programs and benefits and need for the coverage due to current educational efforts for consumers, providers, and State and community organizations. In the past, there were fewer educational activities and current elders have little understanding of the programs. For instance, the Navajo Nation SHIP educational component has only existed for five years. Additionally, the Navajo Nation SHIP has received additional outreach funds from the Arizona and New Mexico SHIP programs in the last couple of years through legislative lobbying.

# Strategies to Increase Enrollment in Medicare and the Medicare Savings Programs

The Navajo Nation SHIP conducts door-to-door public benefits program outreach and often does outreach at Navajo Chapter Houses, Senior Centers, or in conjunction with local Social Security representatives conducting their own outreach on the Navajo Reservation. The SHIP has also partnered with AARP to conduct program outreach.

SHIP program staff advertises availability of program training through flyers and contacts at IHS and Tribal facilities but "leaves it up to PBCs" to request training. The interviewee said the SHIP generally conducts program training once a year.

The SHIP interviewee provided several suggestions for increasing Navajo enrollment in the Medicare and Medicare Savings Programs:

- Educate and train all levels of health care providers on program details. This would enable health care providers to relay accurate program details to patients (e.g., they should be able to tell elderly patients that Medicare "doesn't cover prescription drugs but it does cover some health services, such as XX, that you need.") The SHIP interviewee has found that a convincing message is to inform elderly AI/ANs that Medicare will pay for a large amount of the care provided during a two-to-three-day non-IHS hospital stay.
- Promote community awareness and education about the benefits of the programs. One idea the SHIP interviewee suggested is to place Navajo-language educational videos in IHS facility waiting rooms and perhaps even in non-IHS facilities that AI/ANs use (e.g., he said many go to Flagstaff and Gallup private hospitals although they cannot pay their bills). Because a majority of elderly AI/ANs uses IHS facilities, it would be best to use this system for education and outreach. Senior Centers would also be a good focal point for video distribution. He noted that print materials in Navajo language would not

be very useful because many elderly AI/ANs are illiterate in English and Navajo. Faceto-face or visual materials would likely be much more effective.

• Train IHS hospital volunteers to educate patients about the programs. The SHIP interviewee noted that a lot of old and young AI/ANs volunteer at IHS hospitals and might be used to supplement PBC patient education efforts. A small stipend to reimburse them for transportation or other small expenses would help support such a program. He emphasized that many of these volunteers are known to patients and have already earned their trust, which is important to effective AI/AN outreach.

#### **Inter Tribal Council of Arizona**

### Overview

The site visit team interviewed Inter Tribal Council of Arizona (ITCA) staff that included the Director of Public Benefits Outreach, the Aging Programs Specialist, the Project Specialist for the National Family Caregivers Program, and the Director for Arizona's Region 8 Area Agency on Aging (AAA). Because of the make-up of the group, the discussion focused on AI/AN elder issues and programs.

ITCA interviewees first noted that although ITCA headquarters are in Tucson, the ITCA represents and conducts outreach with Arizona Tribes but not with AI/ANs residing in Arizona's urban areas. Through its Public Benefits Outreach projects, the ITCA provides Medicare and other public benefits training for Tribal staff, runs booths at public events that Tribal members are likely to attend, and places volunteers on Reservations throughout Arizona for outreach and technical assistance. ITCA staff provides a large variety of services to Arizona Tribes as described previously in the report. Specific duties described during the interviews include oversight of the Title VI and Title III grants, the provision of technical assistance to Tribes, and Tribal updates concerning legislation on aging issues. The ITCA's National Family Caregivers Support program also oversees home and community-based services and grants, provides frequent training on these services to professionals, and helps providers enroll in AHCCCS so they can bill Medicaid for providing home and community-based services under the program. Additionally, the director of the AAA programs and SHIP coordinator works with Arizona member Tribes and the Navajo Nation AAA to advocate for AI/AN elders' issues, develop outreach projects, administer AAA-funded programs, develop and implement Medicare training programs for Tribal elders, and oversee SHIP volunteers and training. He also participates in the new State-sponsored coalition, "End of Life Issues," designed to educate professionals and families about cultural end-of-life issues and financial planning and services.

The ITCA directs the Public Benefits Outreach (PBO) project funded by the IHS, CMS, and Arizona's DES Aging and Adult Administration. The project helps Tribal elders, people with disabilities, and their families learn about Social Security, Medicare, Arizona Long Term Care, and other benefits to which they might be entitled. It educates the community and family on assisting elders and people with disabilities on answering benefits question and assists with the appeal process if claims are denied. ITCA developed the project based on input from meetings with elders and Tribal program staff. The PBO project recruited coordinators from the ITCA's member Tribes and provides benefit training for the coordinators, who in turn provide

benefit counseling to AAA clients. The PBO Project also conducts "door to door" outreach on Tribal lands to enroll homebound clients in benefits programs and holds presentations on Reservations to provide consumer information on Medicare and other public benefit programs.

The ITCA also noted that it participates in several working groups that include IHS and CMS staff whose purpose it is to improve outreach programs in Tribal areas across Arizona. The ITCA believes it has a very good working relationship with the Arizona AHCCCS office, particularly with its Native American Coordinator. ITCA interviewees noted that the Native American Coordinator attends all of the ITCA training sessions when asked to participate. They further said that she is very cooperative, has a good relationship with Tribes, and "everybody likes her."

# Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

ITCA interviewees said they believe that most eligible Arizona Tribal members are enrolled in Medicare Part A although some do not realize they have this coverage. This is often because a person does not read his/her mail. When ITCA encounters such cases, they tell the person to ask his/her local senior center or Tribal health director to read all "official looking" mail. Another barrier discussed included a significant lack of computer systems and technology in Tribes to bill third parties. They said only four of their member Tribes currently have computer access.

ITCA interviewees believe under-enrollment of Arizona Tribal members in the Medicare Savings Programs is a substantial problem for the following reasons:

- The primary reason is that many AI/ANs cannot complete the application forms without in-person assistance. ITCA directly and in cooperation with AARP volunteers helps Tribal members complete forms in-person on Arizona Reservations. However, interviewees said that often persons cannot find or obtain the documentation needed. (ITCA provides elders with folders, asks them to "throw all their official looking mail in it," and then bring the folder to a local Senior Center for assistance). Some do not even have a Social Security number, an official marriage certificate (if they had a "Tribal marriage" for instance), a birth certificate, or other required documentation.
- Another barrier is that some Tribal members are not U.S. citizens, particularly from Mexican border Tribes, such as the Tohono O'odham and Pascua Yaqui.
- There tends to be "lots of phone run-around between SSA, CMS, and Medicaid offices" when individuals or advocates on their behalf are trying to get detailed program information. Because of acute and persistent transportation problems, interviewees stressed that it is extremely important that the system work well. Some Tribes have transportation programs, but the assistance may not be well coordinated.
- AI/AN elders may be reluctant to use a toll-free telephone helpline system, preferring face-to-face contact instead.

- The ITCA can provide limited legal assistance to start an appeal process for program denials but then the person requires a referral. Although some Tribes offer legal services, it is neither easy nor inexpensive for AI/ANs to obtain legal representation.
- A lack of programs for short-term childcare that allow AI/ANs to access enrollment sites and health services creates some barriers to third-party program and use. (ITCA is looking into providing some type of support system, particularly for grandparents raising grandchildren, which is a very common situation in many AI/AN communities.)

ITCA interviewees do not perceive Medicare Savings Programs redetermination to be a large problem. ITCA staff work with Tribal contacts and volunteers to keep track of and assist elders with redetermination. The only barrier they commented on is that some Tribal members receive periodic gaming revenues, causing them to cycle in and out of Medicaid eligibility.

# Strategies to Increase Enrollment in Medicare

ITCA staff said they regularly conduct Tribal training and presentations on the Medicare program targeted toward SHIP and ITCA volunteers, elders, and intermediaries (such as health facility staff, Title VI staff, social workers, etc.). They try to coordinate training with other AI/AN elder activities and meetings that may already be planned across the State. ITCA is in the process of creating videos for Tribes about the Medicare program in both English and some Tribal languages (e.g., Hopi and Tohono O'odham languages). ITCA staff attend CMS's "Trainthe-Trainer" program each year and use much of the materials obtained from the program in developing their own training materials. However, ITCA staff also said they develop some of their own materials, including a flyer provided to Tribal members in their homes. ITCA invites CMS, SSA, Federal and State disability program staff and "other CMS partners" to present information at the ITCA training sessions. They said much of their training focuses on raising awareness of available public benefits programs for elders and disabled persons. ITCA also provides Tribal CHRs with brochures and flyers to give to clients.

ITCA interviewees said they are aware that the State provides some funding assistance for outreach, particularly through home and community-based services programs; that the AHCCCS Native American Coordinator provides training and materials; and that Arizona's SHIP also provides Medicare program training and application assistance. In addition to these strategies, and their own outreach activities, ITCA interviewees suggested that the following would help to increase enrollment in the Medicare and Medicare Savings programs among AI/AN elders:

• Provide training and technical assistance for Tribal use of computers for third-party billing purposes and Internet access. This would enable more Tribal members to use such programs as The National Council on the Aging's (NCOA) "Benefits Check-Up" website. The ITCA is currently working in partnership with the NCOA to revise Benefits Check-Up contact information to include local community contacts that can provide in-person or local telephone assistance. When completed, website visitors will not have to contact several agencies in several cities to locate assistance.

- Expedite reimbursement processes through development of computer and/or Internet services. Interviewees said this would provide incentives for Tribal and IHS facilities to encourage third-party program enrollment. The ITCA is working with Tribes to develop these processes and currently much of the third-party Tribal billing goes though ITCA. The ITCA has bought computers for Tribes but does not have enough staff or funding to train Tribes on how to use them. Additional funds for technical assistance would help. They noted that there is a particular lack of knowledge concerning computer and Internet use among rural, isolated Tribes because of their poorer access to computers and telephone systems.
- CMS facilitate, rather than create, materials for use by Tribes and other AI/AN organizations. ITCA interviewees said that AI/AN organizations are likely to be much more effective at designing culturally appropriate materials.
- Increase consumer education and awareness of the programs. Interviewees said that in-person outreach is likely to be most effective, although Tribal and local community radio stations can be an effective way to disseminate program information.
- CMS or the State provide funds directly to ITCA to train community volunteers and provide them with a transportation stipend and to pay a part-time volunteer coordinator. ITCA interviewees believe that a stipend would help ITCA better recruit and retain volunteers. Also, the State requires SHIP and other formal volunteers to fill out reports/forms, which discourages volunteers, but a stipend might help offset this burden.
- Provide funds for a copy machine and fax machine for each Tribe. Interviewees said this would help local volunteers, CHRs, social workers, and other Tribal advocates and workers to better assist in-home and local collection of required application documents.

## Other Issues

ITCA interviewees noted that they would like assistance from PBCs in training and presentations, but said that ITCA currently does not have a partnership with IHS. They believe this is a problem among all Tribes and IHS areas in Arizona, including Navajo Nation. They suggested that a revision of the Intergovernmental Agreement with CMS and IHS to reflect closer partnership relationships between IHS and Tribes might help address the issue.

### FINDINGS: NAVAJO NATION

### Overview

The Navajo Area IHS (NAIHS) is responsible for the delivery of health services to AI/ANs residing in portions of Arizona, New Mexico, and Utah. NAIHS is primarily responsible for providing health care to members of the Navajo Nation and Southern Band of San Juan Paiutes, but also provides care to other AI/AN Tribes (e.g., Zuni, Hopi). Interviewees estimated that less than four percent of the NAIHS service population is non-Navajo.

During the three-day site visit on the Navajo Nation Reservation, the site visit team met with a large number of IHS and Tribal staff from the five Arizona IHS Service Units of the

NAIHS (Ft. Defiance, Chinle, Kayenta, Tuba City, and Winslow; see Appendix III.A for a list of names and contacts). Interviewees also included out-stationed DES eligibility workers at the five Service Units. Three of the Service Units provide care directly through IHS-operated facilities; Navajo Nation began operating all health facilities in two of the Service Units (Winslow and Tuba City) under a 638 contract with IHS in September 2002, a month before our site visit. Long-term care and behavioral health programs are Tribally directed in all of the Service Units.

According to NAIHS staff, there has been a large increase in NAIHS Medicaid revenues over the past three years, totaling \$99 million in 2002. Most Medicaid growth has occurred in Arizona and New Mexico rather than in Utah, primarily because Utah has poorer Tribal consultation. NAIHS interviewees also said there is little Tribal consultation with the State of Utah regarding the State's SCHIP program and they are expecting little, if any, reimbursement from it. NAIHS staff noted that increased Medicaid billing in Arizona and New Mexico could be partially attributed to a change in the late 1990s when the IHS Director made a commitment to maximize third-party resources. Increased funding for this purpose is allowing NAIHS to invest in consultants and computer systems (e.g., the "E-series" program at Ft. Defiance now interfaces with State enrollment data) that enable it to more effectively bill third-party insurance programs.

Interviewees at the Tuba City Service Unit said that the "638" facilities are placing even more emphasis on third-party resources. Winslow Service Unit interviewees estimate that about 50 percent of their revenues will be derived from third-party resources in 2003 due to their improved electronic enrollment and billing systems. NAIHS staff also partially credited the passage of Arizona's Proposition 204 in November 2000 that expanded AHCCCS eligibility for increased Medicaid third-party revenues to Tribal and IHS facilities.<sup>49</sup>

The State of Arizona assists with AHCCCS and KidsCare enrollment and billings through its funding of several DES eligibility staff on-site at Navajo Nation health facilities: Ft. Defiance and Tuba City have a DES eligibility worker on site; Winslow has had a DES worker on-site since 2000 but interviewees said applications are not always processed in a timely manner; Kayenta has an on-site DES worker and a Utah Medicaid eligibility worker; and Chinle used to have two on-site DES eligibility workers but recently lost one.

NAIHS staff interviewed reported that Navajo Nation has good relationships with the Arizona and New Mexico State governments, but not with Utah. Interviewees at Chinle also reported this and Kayenta interviewees noted that Arizona's Medicaid program provides much better coverage and better eligibility requirements than Utah's program. While Tuba City interviewees echoed NAIHS sentiments, they also said that, "Sometimes it's very difficult to get information from AHCCCS when it's needed."

### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Among the five NAIHS Service Units, there was general agreement about the seriousness of Medicaid and SCHIP under-enrollment and the primary reasons for under-enrollment.

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<sup>&</sup>lt;sup>49</sup> Proposition 204 allocates State funds derived from tobacco companies as part of a lawsuit settlement to expand AHCCCS eligibility.

Therefore, interviewee reports are summarized below unless a particular barrier or departure from the rest of the Service Units is important to note.

The five Service Unit interviewees agreed that there are few problems with underenrollment of area AI/ANs in New Mexico's and Arizona's Medicaid programs and that Arizona has an excellent Medicaid program. They did report, however – particularly in the Service Unit closest to the Utah border (Kayenta) – a significant challenge in enrolling AI/ANs in Utah's Medicaid program. Interviewees said that patient registration staff at most NAIHS health facilities screen patients for all third-party insurance eligibility, then refer them to Patient Benefit Coordinators (PBCs) for additional screening and application assistance. As well, out-stationed AHCCCS DES eligibility workers help with application completion for the AHCCCS program.

In contrast, interviewees from several of the Service Units believe there is serious underenrollment in all three State's SCHIP programs, particularly noting that Utah and Arizona have capped enrollment. State a staff said that Utah's SCHIP enrollment was closed until November 2002. Interviewees provided reasons for SCHIP under-enrollment that included individuals having some sort of private insurance, SCHIP is a new program, it is targeted toward a young population, and/or it is not well advertised.

There was general agreement among the five Service Unit interviewees that the largest enrollment "gaps" are most likely associated with AI/ANs who do not use IHS or Tribal facilities. Because there is little or no outreach to non-patients, and uninsured people are only screened when they present at health facilities, "healthier" eligible AI/ANs and those living in rural areas (which are hardest to reach) are the most likely to be under-enrolled in Medicaid, SCHIP, Medicare, and the Medicare Savings Programs.

### Barriers to Initial Enrollment

NAIHS staff and Service Unit IHS and Tribal staff interviewed at the five Arizona Service Units discussed a variety of barriers to Navajo Tribal enrollment in the Medicaid and SCHIP programs in Arizona, New Mexico, and Utah:

• One of the most prevalent barriers discussed is Navajo Nation's having to work with three (and sometimes four) different State Medicaid programs and three different CMS regions. (In addition, some Tribal members use Colorado health care facilities because they are closest.) It is very difficult to communicate with and educate so many people about the three States' Medicaid programs and structures. Additionally, interviewees noted that obtaining State-level data from all three States can be difficult, as is coordinating IHS facilities across the States. Examples of difficulties include:

near future (telephone conversation, July 16, 2003.)

<sup>&</sup>lt;sup>50</sup>In response to this Statement, CMS noted that it has not been notified that Arizona's KidsCare has capped enrollment. Arizona's AHCCCS/KidsCare Native American Coordinator confirmed that, although the State statute creating its SCHIP program allows for capped enrollment if State and Federal funds for this purpose are exhausted, KidsCare enrollment has to date not approached the enrollment cap and is unlikely to be capped at any time in the

<sup>&</sup>lt;sup>51</sup>Utah SCHIP enrollment has been capped since December 7, 2001, and no new applications are being accepted; however, SCHIP may hold periodic open enrollments announced by public notices. The last open enrollment was held November 12 - 22, 2002. http://health.utah.gov/chip/benefitreductions.htm, accessed March 14, 2003.

- Kayenta needs to send inpatients to hospitals with an available bed but this causes a billing problem if a resident of one State is referred to a hospital in another State.
- Navajo IHS facilities that treat patients from border States have to interpret Medicaid rules and regulations from up to four different States.
- Services provided to an out-of-State Navajo by an IHS facility but delivered by a private hospital or provider often go un-reimbursed because the hospital or provider does not contract with the patient's resident State Medicaid office.
- Chinle staff noted differences in the way various State human services agencies handle medical assistance programs. Staff feels that duplication of work and services exists; this duplication could be minimized by increased coordination and communication among State agencies within and across the three States.
- Kayenta staff said that State border issues are exacerbated by the lack of Medicaid providers in all four States. For example, Utah patients often drive to Farmington, New Mexico, for renal dialysis because it is the only place in the area that accepts Medicaid patients. However, New Mexico providers do not want to go through the Utah Medicaid process to become certified as Utah Medicaid providers. Additionally, they receive more money for these patients from IHS's Contract Health Services than from Utah's Medicaid program.
- Tribal members must apply for Medicaid/SCHIP programs in their resident State as well as in the State in which they receive treatment.
- County-to-Tribal government relationships are even more difficult to establish and maintain than State-Tribal government relationships, which must be negotiated among four States.
- Many Navajos view IHS as a "free" health care system so they do not see why they should enroll in other government health care/insurance programs. For instance, Tribal members view Contract Health Services as an "entitlement" and they like it because they "don't get the run-around." Additionally, many people are suspicious about the need to provide certain application information to government agencies, including Social Security numbers, employment history, and income.
- Substantial lack of Tribal members' awareness and program education is a major barrier for all of the States' programs. Awareness of the three States' SCHIP programs was noted as a particular problem. Interviewees also said that even people who are aware of the programs, because PBCs and patient registration staff provide continuous education, often do not fully understand their benefits or why they should enroll until they visit an IHS or Tribal facility and have the programs explained to them.
- Low program awareness, according to interviewees, is also due to a lack of access to communication devices on the Navajo Reservation, such as televisions, telephones, and radios. Interviewees noted that as few as one-third of Tribal members have telephones or radios in their homes and even fewer have televisions.

- Communication and transportation problems contribute significantly to enrollment barriers in all of the five Service Units, but particularly in the more remote areas of Chinle, Kayenta, and Tuba City. Kayenta interviewees stressed that communication with Tribal members is a large challenge due to illiteracy and language issues (particularly for older Navajos), as well as lack of mail, electricity, telephone service, and applicants providing wrong addresses. A very significant problem in most areas of the Navajo Reservation is lack of access to reliable transportation to travel to a DES office to enroll or to return for follow-up appointments to complete the enrollment process. Most AI/ANs living on the Reservation also lack the ability to enroll in programs via Internet or mail. Illiteracy that inhibits many area AI/ANs' ability to complete applications by mail was also cited as a barrier. Finally, even when Navajo Tribal members do have transportation and communication capabilities, many are deterred from enrolling in the programs because they do not have reliable enough transportation to use the services on a regular or even periodic basis.
- The remoteness of many Reservation communities, poor road conditions, and lack of reliable transportation often results in "crisis care." That is, many Tribal members do not understand the value of Medicaid or SCHIP benefits if they have not needed to access them in the past. As such, they do not receive many preventive services available through these programs (and interviewees noted that many health crises are the result of no preventive care). The cycle of "crisis care" costs hospitals and health centers in the form of non-reimbursable care. Several interviewees also said that the October 2001 law allocating responsibility to State DES offices to determine AHCCCS eligibility has caused some enrollment problems. They said there are fewer DES offices than there were County offices and that DES regions do not overlap with IHS regions, creating a "long haul" for many to get to these offices. (Tuba City and Chinle interviewees also cited difficulty with receiving timely information from DES regarding patients' eligibility status.)
- Many interviewees cited lack of infrastructure on the Navajo Reservation as a significant program enrollment barrier. Navajo Nation leadership said that the Navajo Division of Health does not have an appropriate encounter and billing infrastructure, including staff and computerized billing mechanisms (most billing is still done by hand). This reduces incentives to promote program enrollment. Additionally, leadership stated that there are no coordinated systems in place for Navajo Nation to provide outreach and enrollment assistance. For example, they noted that no single entity is responsible for health outreach and enrollment services, stating that this leads to "crisis management."
- Navajo Tribal staff and interviewees at Chinle cited the lack of infrastructure for training, program development, and information sharing as a barrier to program enrollment. Tribal staff also said that Navajo Nation has not developed a strong enough infrastructure to support coordination and integration of health care services and aftercare services.

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<sup>&</sup>lt;sup>52</sup>Prior to passage of Proposition 204, Arizona's 15 counties were responsible for determining individuals' eligibility for the Medicaid and SCHIP programs. Effective October 1, 2001, Medicaid expansion absorbed all State-funded programs and the Arizona Department of Economic Security became responsible for determining program eligibility.

Without this, staff does not consider it a good idea to develop training and education programs to increase enrollment.

- Other interviewees cited that a lack of infrastructure for information sharing among NAIHS Service Units in particular is problematic for Navajo health facilities and Tribal offices. Currently, the only Tribal office on the Reservation with Internet access is at Window Rock. Mechanisms for information sharing would help health centers and Tribal offices communicate with each other and provide a coordinated continuum of care to Navajos. Improved communication capabilities would also help patient resource staff keep current with frequent changes in Medicaid programs. Kayenta staff remarked that the rapid and numerous policy and administrative changes within Medicaid in the three States are confusing. They cannot adequately help Navajos understand these changes if they themselves are not aware of or do not understand them.
- Difficulties with program application processes were also often cited as barriers to enrollment.
- Interviewees from three of the five Service Units said that all of the three State's Medicaid and SCHIP applications are too lengthy and time-consuming, involving too much paperwork and required documentation. Kayenta staff mentioned that applications are too dependent on individuals' providing information and documentation. They feel that applications should be computerized, with the ability to pull information needed for the applications from other agencies' databases.53
- Interviewees also often cited poor customer service at DES and SSA offices as barriers to program application. Interviewees from all Service Units stated that Navajo members who have gone to local DES and SSA offices to apply for programs report poor customer service. Specifics mentioned by interviewees include: lack of culturally competent service including insensitivity to AI/AN health care needs or ways of having those needs met; perceived negative attitudes and lack of customer services skills; perceived racial bias and intimidating behavior; and failure of County/State workers to provide application assistance. (Navajo Nation staff interviewees said that the Winslow Service Unit has documented instances of these problems.)
- Winslow and Chinle interviewees said that Arizona does not conduct a comprehensive evaluation for eligibility even though it uses a universal form for its AHCCCS programs and KidsCare, stating that the form is not shared universally among agencies (this was not documented).
- Chinle interviewees reported that enrollment in KidsCare is a challenge for several reasons including difficulty communicating with DES offices to verify application and redetermination information, and KidsCare redetermination notices arriving after deadlines have passed.
- Navajo Nation staff interviewees said that SCHIP eligibility decisions in Arizona (they did not comment on the other States) are often too slow (e.g., when they are asked to send

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<sup>53</sup> Note that AHCCCS and KidsCare applicants can apply on-line.

an application to Phoenix, it can be re-routed to the Dilkon DES for eligibility determination).

- Navajo Nation staff interviewees also said that a very large problem is that no AHCCCS or KidsCare decision letter is sent to applicants (they did not comment on the other States). They said that the Winslow Service Unit has documented this problem.
- Tuba City staff cited DES's lack of a screening tool for eligibility as a deterrent to enrollment in AHCCCS and KidsCare. Currently, DES workers distribute applications to anyone who seeks one without first investigating eligibility criteria. As such, more people are denied for programs than would be the case if DES staff reviewed eligibility criteria on an individual basis before initiating the application process. If DES were to utilize a screening tool, Tribal members would have a better idea of the likelihood that they are eligible, causing more individuals to follow through with the application process.
- Kayenta staff noted that lack of reliable transportation options for the Reservation population is exacerbated by limited DES office hours.
- Navajo Tribal staff commented that the lack of a true government-to-government relationship between Navajo Nation and the U.S. government filters down to the County level. Staff reported a poor relationship between the Tribe and County governments that overlap the Reservation. The fact that the Federal government has delegated Medicaid administration to the States, some of which in turn have delegated this authority to County offices, exacerbates this tension and presents barriers to enrollment. Tribal staff also feels that many State regulations do not honor and respect Tribal programs, resulting in many State policies not being conducive to Tribal enrollment in Medicaid and SCHIP. According to interviewees, the poor relationship between the Tribe and County, State, and Federal governments feeds some members' historical mistrust of these governments; they are suspicious about providing personal information and would rather forego the services a program offers than provide the information necessary to enroll in that program.
- Several interviewees stated that Navajo Nation's agreement with the State's Division of Child Support Enforcement deters many potential beneficiaries from enrolling in Medicaid and KidsCare. A significant number of Navajo grandparents are raising grandchildren and fear that their KidsCare application will trigger DES to contact the absent parent for child support (Chinle interviewees said this "is a huge problem"). Separated parents are also asked to apply for child support but many are afraid of the repercussions of doing so.
- Also, some AI/AN grandparents need short-term daycare assistance so they can go to DES offices (not realizing they can mail in the application if they can complete it without assistance). At the time of the site visit, interviewees were not aware of any programs offering daycare assistance.

III-30

<sup>&</sup>lt;sup>54</sup> Navajo Nation Tribal health staff has policy briefs on the issues discussed in this bullet point that are available upon request.

• Some interviewees remarked that welfare stigma could be a barrier to Medicaid and SCHIP enrollment. Chinle interviewees said that this stigma is particularly acute for the KidsCare program because applicants are embarrassed to be seen at a DES office. Although most Navajos feel comfortable going to a Reservation health facility to apply for SCHIP or Medicaid, several interviewees said that their on-site DES workers are overburdened (or virtually non-existent in the case of Utah).

The following program enrollment barriers were reported by only one or two interviewees:

- Navajo Nation leadership called for additional program training for service providers.
   They also said they do not receive AHCCCS program updates as regularly as they should.
- Ft. Defiance interviewees commented that the Arizona AHCCCS has improved communications recently, but they still have significant communication problems with local SSA/SSI offices.
- Winslow, Tuba City, and Fort Defiance interviewees cited confusion about Navajo Nation's Tribal insurance (covering an estimated 6,000 employees of Navajo Nation and their dependents) as a barrier to enrollment. Some individuals who are covered under the Tribal insurance program are unaware that they can also receive Medicaid benefits. As well, facilities that provide care to these individuals face billing obstacles: interviewees reported that the Arizona AHCCCS program considers Tribal insurance to be private insurance and has begun to deny claims for Navajo AHCCCS enrollees who are also enrolled in the Tribal program (this was not documented).

### Barriers to Maintaining Enrollment

Redetermination for the three States' Medicaid and SCHIP programs was not often discussed as a major problem for Navajo Nation members. Kayenta interviewees did mention that redetermination often causes AI/AN Medicaid beneficiaries to fall off the Medicaid rolls. Staff said that caseworkers in DES offices are all different, with some willing and some not willing to contact recipients whose enrollment periods are about to end. Interviewees discussed the following specific barriers to maintaining enrollment in these programs:

• Fort Defiance and Tuba City staff cited the billing cycle of Arizona's AHCCCS program as a barrier to maintaining enrollment. The New Mexico Medicaid program allows a 90-day window within which the agency will reimburse Medicaid claims. In Arizona, DES requires a bill within seven days of the service. This short timeframe presents challenges for health centers that lack electronic billing systems or whose billing systems do not generate bills within the required timeframe. For instance, the billing system at the Tuba City facility does not generate a bill for thirty days, far later than DES' seven-day requirement. The fact that some facilities know that they cannot generate a bill in time to receive reimbursement deters them from submitting a bill at all. Furthermore, these facilities have little incentive to encourage people to enroll in programs, to stay enrolled after an initial enrollment period, or to present alternate resources at the time of the visit.

- Staff at Kayenta said that seasonal employment causes many AI/AN Medicaid beneficiaries to cycle on and off the program.
- Kayenta staff noted that the Utah Department of Health's Primary Care Network (PCN) requires a \$50 annual enrollment fee. <sup>55</sup> Because PCN contracts with the Utah Medicaid program as a provider, AI/ANs who want to use PCN providers are faced with a \$50 annual fee. This fee is prohibitive for many AI/AN families.
- Tribal members sometimes do not return redetermination forms due to problems with obtaining supporting documentation.
- Chinle interviewees said that the AHCCCS and KidsCare redetermination processes are "vague and arrive too late to the family." This requires PBCs to do time-consuming follow-ups every 30 days with every family until their children are enrolled or denied.

### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

With the exception of the Kayenta Service Unit interviewees, others stated that Medicare and Medicare Savings Programs under-enrollment is not a large problem in their area. AI/ANs who are eligible but not enrolled are either referred to the local SSA office or PBCs at health care facilities who explain program benefits and processes and help complete applications. Kayenta interviewees said Navajos in their area are significantly under-enrolled in both Medicare Parts A and B and the Medicare Savings Programs. They attributed this mainly to the fact that "Tribal members tend to look to IHS to help with everything."

Despite relatively low estimated under-enrollment in these programs in most areas of the Navajo Reservation, interviewees said the following obstacles prevent 100 percent enrollment of all eligible Tribal members:

- Tuba City and Kayenta interviewees stated that under-enrollment in Medicare Part A is often due to a widow's lack of awareness about her husband's work history. Even if aware of potential eligibility for Medicare via a spouse, many widows do not know where to seek help for information about how to access services. Additionally, interviewees said there is little information regarding Medicare eligibility for disabled persons. Staff reported that some do seek help at an IHS facility, noting that many AI/ANs look to the IHS for every health care need and every question about health care coverage. While IHS patient resource staff is willing to help search for information and refer individuals to the appropriate agencies, they also suggested that out-stationed DES and SSA staff at the health facility would ease the burden of the resource staff's workload.
- Tuba City staff cited the fact that some spouses who may be eligible for Medicare Part A do not have a formal marriage certificate and do not realize there are other ways they can prove their marriage to receive Medicare Part A. They suggested this is an issue that Tribes should help resolve.

III-32

<sup>&</sup>lt;sup>55</sup> Navajo Nation submitted a position paper to the Utah Medicaid office opposing the \$50 annual enrollment fee required by PCN.

- Chinle staff noted that while many elders or disabled Navajo members may be eligible for the Medicare Savings Programs, Social Security Income (SSI) staff at SSA offices does not educate clients about these programs. Even if an individual expresses interest in the Medicare Savings Programs, SSI staff hand out an application but do not offer any assistance with it. Because many elders require help with the application due to language barriers, illiteracy, and the lengthy SSI application and substantial documentation required, those who cannot find assistance elsewhere are often unable to complete the application. Letters from SSA explaining program acceptance or denial or requesting additional information are difficult for many Tribal elders to understand due to lack of education and language problems. Additionally, interviewees gave examples of how cultural misunderstandings can hinder enrollment. For example, interviewees said that the living arrangements of AI/ANs are sometimes different from others so when an SSA representative asks these types of questions, the answers seem awkward or unusual to the representative who then assumes that the person is not eligible. Kayenta interviewees noted that its local SSA's office recent hiring of Navajo speakers has been very helpful.
- Tuba City, Kayenta, and Chinle staff pointed out that the Medicare Part B premium is high relative to the incomes of many Navajo residents and that many beneficiaries are unwilling or unable to pay the premium since they think they can obtain all Part B services through IHS. They often do not pay the premium until they are sick and realize the need for it, but then a penalty premium applies. Even if they were eligible for the Medicare Savings Programs that would pay the premium and co-pays for them, many Navajo members still do not want to enroll in these programs. They do not understand the funding mechanisms of IHS facilities or the way that enrolling in a program would benefit the facility, themselves, or their Tribe. They find the idea of enrolling in Medicaid and Medicare confusing and redundant to the care they can already receive through IHS for "free." Chinle interviewees said that even the agencies themselves do not seem to understand the Medicare Savings Programs well and how Medicare and Medicaid interact.
- Fort Defiance, Chinle, Kayenta, and Navajo Tribal staff cited language as a significant barrier to enrollment for elderly Tribal members. Navajos are a traditional people and many elders still speak only the Tribe's native language. In fact, many of these elders are illiterate even in their native language. As such, printed materials in the Navajo language would not help increase their knowledge about public health insurance programs. Most of the agencies that handle program enrollment do not have bilingual staff to help these individuals with Medicare issues.
- Kayenta interviewees cited a lack of coordination between DES and SSA as a barrier to enrollment although they did say that DES has a connection to SSA on-line.
- Tuba City interviewees said that some Tribal employees' records are not in the SSA database, causing them to appear ineligible for Medicare.

# Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

Interviewees discussed several activities that currently take place on the Navajo Reservation that help increase program enrollment:

- Ft. Defiance staff does not mandate but strongly encourages patients who need Contract Health Services to enroll in Medicaid, SCHIP, and Medicare programs.
- Ft. Defiance PBCs reported that they are careful to document the steps they have taken with an application so that other hospital staff can track the application process if there is a change or turnover in personnel. This type of documentation is important so that individuals receive a continuum of assistance from patient resource staff.
- PBCs in the Gallup IHS hospital have started an internal meeting among Navajo Service
  Units to communicate with each other and coordinate among PBCs. Gallup IHS hospital
  staff has access to other Navajo Area Service Units' patient data and Ft. Defiance staff
  has access to insurance information for the other Service Units. Interviewees noted that
  the computerized capacity that has allowed sharing of data and information systems
  among clinics has been very helpful for increasing enrollment.
- Ft. Defiance interviewees feel that IHS as a provider is doing a good education and enrollment job, but other providers serving this same population are not doing as much. They also believe that Navajo Area IHS facilities have worked hard to automate billing of third-party resources.
- Chinle IHS hospital has two PBCs on staff and is soon hiring four additional ones. After this occurs, they said they will work on conducting more outreach to non-user AI/ANs and linking through the Internet with other Service Units and Navajo Division of Health staff.
- Ft. Defiance interviewees said that the State of Arizona has done some KidsCare outreach, but has not developed or implemented a comprehensive, well-coordinated approach to outreach. Tuba City interviewees stated they are not aware of any Arizona outreach programs for AI/ANs for the AHCCCS or KidsCare programs.
- Tuba City interviewees said that in Arizona, PBCs can go directly into the AHCCCS database to view begin and end dates of enrollment and eligibility determinations. As well, health facilities' billing offices can view AHCCCS payments. In addition, a downloadable AHCCCS eligibility roster is sent to them once a month but only includes those enrolled in an IHS/Tribal health plan but not in other AHCCCS health plans. The eligibility roster provides information on race and whether the person is living on or off-Reservation.

Similar to the discussion of enrollment barriers, interviewees from the five Navajo Area Service Units, the Navajo Area IHS Office, and Navajo Nation staff recommended several common strategies for improving Tribal enrollment in Medicaid, SCHIP, and Medicare programs. These recommendations are summarized below. At the end of the list are several strategies that were suggested by only one or two interviewees.

• Establish a tri-State Medicaid agency for Navajo Nation. All interviewees expressed support for the establishment of an IHS- or Tribally-run tri-State Medicaid agency that would serve the Navajo Reservation exclusively. The IHS and Tribes would have the ability to determine eligibility for Navajo members. Interviewees said that the Area IHS and Tribal communities are more informed about AI/AN issues than most DES staff and could increase enrollment by employing culturally competent enrollment strategies. Also, the administrative difficulties affecting health facilities located near State borders would be eliminated. A tri-State Medicaid agency for Navajo Nation, according to interviewees, would bring more comparability across State programs and structure and promote government-to-government relationships by taking County governments "out of the equation."

Interviewees were not sure how this could be accomplished, but Service Unit interviewees suggested that Navajo Nation leadership should investigate State waivers for operating their own TANF and Medicaid programs. Several mentioned that they currently employ Tribal staff as eligibility workers and case managers for behavioral health through a Memorandum of Agreement with the State of Arizona. They suggested that perhaps the same could be done for the three States' Medicaid programs.<sup>56</sup>

Navajo Nation interviewees said they currently do not have adequate data to support eligibility estimates for understanding under-enrollment and for targeting outreach. Navajo Nation said they would like an actuarial grant from CMS to do a study of eligibility and costs. Navajo Nation has appropriated some funds to develop such estimates in support of advocating for a tri-State Medicaid program, but do not have enough funds to complete the study at this time.

• Facilitate "one-stop-shopping" capability. Interviewees would like to have on-site eligibility workers from many public benefit program areas such as Social Security, Veterans Administration, all three State Medicaid/SCHIP offices, Food Stamps, State- or Tribally-operated TANF programs, and others (e.g., the Women, Infants, and Children program). Current DES workers can only process applications for limited social services. Several also said that it would be most helpful if on-site out-stationed workers could speak Navajo and/or would live in the local community. In addition, it would be ideal if these workers could operate out of one office or building to simplify applicant access. Interviewees recommended that not only should there be one out-stationed staff from each entity/program at the same place, but that each staff person should be trained to provide support for all the programs. Kayenta interviewees even recommended that the State/CMS construct a software system that would allow for computerized application and that could be accessed from a number of on- and off-Reservations sites, as well as allow program applicants to apply for all eligible programs at one time.

Somewhat related, Ft. Defiance staff cited their case management approach as vital to increasing enrollment in public benefits programs. Patient resource staff work closely with WIC,

<sup>&</sup>lt;sup>56</sup> At the very minimum, interviewees said better coordination of Medicaid/SCHIP programs across the three States is greatly needed so Navajos do not have to provide duplicate application information.

Aging, and health education program staff and the police department to provide a comprehensive network of care to Navajo members. Case management services are also available for off-Reservation Tribal members.

• States and CMS provide systematized information resources support. Interviewees stressed that PBCs need specifics about program enrollment processes and on-line forms and screening tools that would highlight applicant information still needed (e.g., electronically highlighted). PBCs also need access to resources where they can easily and quickly either find an answer or at least know where to get the information. PBCs are currently overburdened and the information resource system is ad hoc. They now rely on CMS and State websites, which can be helpful, but PBCs noted that access to the Internet is not always available or can be very limited (particularly at rural health stations) and is time consuming. Interviewees commented that many PBCs informally now provide "one-stop-shopping" for health facility users but that they need much more systematic access to the "right" tools, information, and training.

Interviewees also requested workforce development assistance that would assist them in hiring health facility staff that already have the relevant skills. The intensive training now required for new patient registration clerks and PBCs consumes a great amount of health facility resources. Some interviewees suggested that development of a training package for a variety of public benefits programs would also help. Others suggested that Tribes and the IHS forge partnerships with local community colleges to develop training programs for PBCs and billing/coding workers. (Gallup College currently provides such training but it is difficult for many Navajos to physically access it). Navajo Nation is currently considering providing on-line courses through the Reservation's telemedicine infrastructure; they suggested that States and CMS might also be able to tap into this system for continuing education and training purposes. They noted that Chinle currently provides Internet courses to health centers for doctors and nurses.

• **Provide greater intermediary training and support.** All those interviewed stressed the importance of, and great need for, increased program training for all types of intermediaries – local community people who are in frequent contact with eligible but non-enrolled Tribal members who could provide screening and application assistance. All interviewees also emphasized that training needs to consist of *comprehensive*, *regular*, *cross training*.

Comprehensive cross-training should encompass both training on a variety of public benefits programs available in Arizona, New Mexico, and Utah (e.g., SSA, SSI, Medicaid, SCHIP, Medicare Savings Programs, Medicare, food stamps, cash assistance, WIC, etc.), as well as training for all types of intermediaries (e.g., Aging staff, WIC staff, Head Start staff which also provide home-based services, senior meals/congregate meals staff, CHRs, AHCCCS behavioral staff and case managers, Tribal health board members, health educators, schools, all IHS and Tribal facility staff – including PBCs, registration clerks, nurses, disability providers, Contract Health Services staff, and case managers). In essence, interviewees suggested that training should be targeted toward the existing staff infrastructure available for family/individual assistance programs.

Several noted, however, that training of PBCs (and Contract Representatives with CHS) are the most important to train because most facilities refer patients to them for assistance and "what they say to patients is what patients believe." Tuba City interviewees reported that IHS and Navajo Nation have both tried to coordinate Navajo Nation PBC training, but this has not yet occurred. Tuba City interviewees suggested that Inscription House's "whole-system staff approach" to third-party resources training might be a good model for health facilities. Additionally, the Ft. Defiance business office management team meets bi-weekly to discuss issues. The high level of communication between the management team members helps them devise strategies to increase enrollment.

Navajo Tribal staff and Chinle staff interviewees noted that Tribal staff, particularly PBCs, must absorb the responsibility of understanding the complicated administrative intricacies of the various State and Federally funded programs in which their members are enrolled. Interviewees feel that there is a lack of County, State, and Federal support to help them fulfill this responsibility.

- Improve agency staff training. Interviewees recommended that cross-training activities should include training of State and Federal agency staff to better understand Tribal systems and culture. Additionally, Chinle and Tuba City interviewees said that DES workers (except those out-stationed at IHS/Tribal facilities) generally do not understand the "spend-down" process for AHCCCS eligibility. Ft. Defiance interviewees said that Navajos generally feel more comfortable talking to a health facility's patient resource staff rather than DES workers because of language and cultural similarities between members and facility staff.
- Use existing Tribal infrastructure to identify potential applicants. Very closely related to the previous recommendations, Navajo Tribal staff suggested that existing home- and community-based services could be a successful avenue for getting information to members who may be eligible but not enrolled in any public benefits programs. Tribal Congregate Meals programs also provide home delivery of meals, serving an estimated 8,000 senior citizens at home in the Navajo Nation. Senior Center staff could be cross-trained on Medicare and Medicaid issues and could present this information to elders at Senior Centers. Head Start, which is a large and important program with Navajo Nation according to those interviewed, could be used as a site to provide information to families. Tribal staff reported that 6,000 families on the Reservation receive Head Start services and are all probably eligible for Medicaid or KidsCare. Other family assistance programs (such as TANF) could also be a source for locating people who are eligible for programs. Ft. Defiance interviewees echoed that there are a lot of untapped resources on the Reservation for enrollment. They also support the use of Navajo family support divisions as a way to reach potential eligible populations and believe that certifying the staff from these programs to determine eligibility would increase enrollment. Ft. Defiance is currently focusing on how to coordinate with Head Start to get more Navajo children enrolled in KidsCare. Many interviewees stressed that community outreach activities need to be targeted at non-IHS/Tribal user populations.

- Increase funds for IHS and Tribal health facilities to hire additional Patient Benefit Coordinators. Ft. Defiance interviewees said it takes a PBC about an hour to give a single patient the information he/she needs to understand the benefits of enrolling in programs and then helping them to enroll. PBCs generally explain the programs in Navajo language; they tell people to bring in any Medicaid/Medicare paperwork to their facility visit for assistance; they help patients complete application forms when time allows. All interviewees said there are not enough PBCs to help all who need it and virtually no PBCs have time to conduct outreach to the non-user population. Chinle interviewees said they have tried to work with CHRs to help relieve the PBCs' workload, but CHRs say their primary function is to help with home personal care and do not have the time to help process applications. Also, interviewees stressed that continuity of staff is important for effective assistance, which is not always the case for CHRs. In contrast, Winslow interviewees said that CHRs are willing to carry out screening/enrollment assistance but need training.
- Improve consumer education. There was unanimous agreement among interviewees that a much greater amount of consumer education about the Medicaid, SCHIP, Medicare, and Medicare Savings Program is needed on the Reservation. Specific consumer education needs discussed include:
- Educating the whole family during a patient encounter and exploring alternative resources with patients;
- "Selling" the benefits of the programs to patients, as well as providing information about benefits available through all public benefits programs, why they should sign up, and how the programs will benefit them individually and their community;
- Educating patients about the high costs of health care. Many have never seen a bill if all of their care has previously been provided through IHS.

The general sentiment of interviewees is that the focus of consumer education efforts should be to "share benefits of the programs and let smart people come to their own decisions about whether or not they want to enroll." Interviewees provided a number of suggestions for ensuring effectiveness of consumer education efforts for Navajos:

- Consumer materials need to employ simple language, written (for younger populations) or preferably spoken (for elder populations) in the Navajo language, using cultural identification techniques (e.g., messages might be written in terms "of a circle" using "indirect" language). Chinle and Kayenta interviewees said they would like flyers, posters, and brochures written in the Navajo language that they could easily and inexpensively disseminate. Tuba City interviewees suggested placing inserts in Tribal employees' paychecks, emphasizing that it is often most effective for Tribal members to receive information from the Tribe than from an external government agency.
- Many of those interviewed find that explaining program details to potential applicants on a one-to-one basis, with the use of visual aids, has been the most successful strategy to encourage enrollment. In general, Navajo people respond best to oral communication or

"visualization" techniques. In the past, IHS has conducted door-to-door outreach in isolated areas using laptops to assist people with enrollment, which seemed to be effective. Chinle and Kayenta interviewees said they are considering creating videos about the KidsCare program that could be viewed in health facility waiting rooms but need funding to do this. Other suggested avenues for in-person consumer education activities included health fairs sponsored by Tribal CHRs and Navajo Nation Chapter House meetings, which are particularly good for rural areas. Ft. Defiance interviewees cited two successful outreach activities they have conducted: offering information about public health insurance programs at a health fair sponsored by Tribal CHRs and setting up a health booth at a travel fair.

- Interviewees had mixed opinions about the effectiveness of radio as an avenue for consumer education. While several interviewees said that radio public service announcements in Navajo could be effective, others said they might not be too useful because many people on the Reservation cannot receive radio signals.
- Tuba City interviewees said that PBCs sometimes use CHRs to relay messages to hard-to-reach Navajo members who may be eligible for public benefits programs. Chinle staff also believe that CHRs could play a particularly important role in increasing Tribal members' awareness of public benefits programs because they regularly go into members' homes. They have tried to work with CHRs in the past but met with some resistance. Some CHRs think that their role should be more "hands-on," preferring to render medical assistance rather than help with paperwork. Interviewees felt that institutionalizing the process or using CHRs to relay messages, as part of the CHR job function, would improve effectiveness of this outreach method.
- All interviewees emphasized that any successful outreach strategy for Navajos requires
  family or community connections, trust relationships, and a knowledge of Navajo
  language to open doors to acceptance and questions. Ft. Defiance staff also stressed the
  importance of coordinated outreach. While they have done some limited outreach
  activities in the past, they have never attempted a comprehensive, well-coordinated
  approach. They believe that such an outreach approach would increase program
  enrollment.
- Increase collaboration/partnerships. The general sentiment among all interviewees was that "everybody, at all levels, needs to play together" to increase Navajo enrollment in public insurance programs. They suggested that while many issues can be resolved through a third-party phone call, there is often a need for on-going regular communication among State, Federal, and County agencies, Tribal health facility staff, Tribal social services staff, and others who work on a daily basis with low-income Tribal members. Communications might be facilitated through in-person meetings, a newsletter, a website, or "anything that encourages on-going dialogue." Many of those interviewed at the Service Units suggested that a "bottom-up approach" might work best in which front-line workers cooperatively construct recommendations to solve global

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<sup>&</sup>lt;sup>57</sup> Ft. Defiance interviews noted that Intergovernmental Affairs exists, but said that regulations and guidelines prohibit some lines of communication and advocacy among agencies.

problems and bring these recommendations to "decision makers" to implement. Interviewees also stressed the need for agreements about lines of communication among agencies, caseworkers, and private insurers, and the need for a group facilitator to strategically ask questions directed to all players. Interviewees suggested that a compilation of existing models of such communication groups could be shared with others to provide ideas on how this type of workgroup might function.

Other recommendations for improving Navajo member enrollment in the Medicaid, SCHIP, and Medicare programs that were suggested by one or two interviewees include:

- Support an additional on-site DES worker. Chinle's health center has had one DES worker on-site for the past two years, but said they need another. However, they said it is very difficult to get a DES worker on site due to general DES staffing problems. DES currently needs to "pull" staff from local offices, which can be difficult because local offices tend to have high workloads. Interviewees recommended that perhaps IHS could provide funds to partially support an additional on-site DES worker.
- Internet capability for health facility workers to access Medicare/Medicaid program changes. Ft. Defiance interviewees requested that States make public any changes in Medicaid benefits. Chinle interviewees said it would be very helpful to have Internet capability for health facility workers to access Medicare/Medicaid program changes.
- Assistance with capacity building and infrastructure construction. Navajo Nation leadership called for assistance with capacity building and infrastructure construction, primarily to support on-line billing, inter-departmental communications, and intra- and inter- agency data systems.
- "Wrap-around services" Several interviewees noted the need for "wrap-around services" to enable more Navajos to access health care services. Wrap-around services include transportation, daycare, and legal services. Navajo Nation leadership said it is beginning to explore transportation issues and how the Navajo Division of Health might be able to help.
- AI/AN liaison. Chinle interviewees called for an AI/AN liaison at DES similar to the AHCCCS Native American Coordinator and the AI/AN Medicaid liaison for New Mexico. Ft. Defiance interviewees also suggested that Utah needs an AI/AN Medicaid liaison, as well as suggested that all three States could use similar liaisons in many other social services departments and divisions.
- Best practices/examples guide and resource manual. Several interviewees suggested the development of a best practices/examples guide for Indian Country. Along similar lines, Ft. Defiance interviewees said that Arizona's social services department has developed a resource manual that explains processes for AI/ANs to provide proof of birth, marriages, etc. They recommended that this manual be shared with other State and Federal agencies and Tribes.

### Other Issues

Winslow Service Unit interviewees strongly recommended that CMS organize a stakeholder group that at a minimum would include Tribal, IHS, urban Indian health, "638" Tribes, State, CMS, SSA, and Veterans Administration representation to discuss the findings and recommendations of the final, cross-cutting report from this project and to create a "high-level" implementation team. They even suggested that CMS make creation of such a workgroup part of the protocol for publicly releasing the report. They suggested that the workgroup could create a strategic plan based on findings from this project that would include a designation of which agency/group would take responsibility for implementing policy, programmatic, communication, and training recommendations contained in the cross-cutting summary report.

Winslow interviewees also requested that CMS provide a continuous forum for discussing recommendations, and implementation of recommendations in the report, suggesting that the annual National Indian Health Board Consumer Conference might be an appropriate forum. Navajo Nation leadership requested that this report include the following Statement: "Indian Country would be willing to outline a strategic plan and provide CMS with direction on how to implement recommendations from the report."

Interviewees at several of the Service Units raised the issue of the lack of billing capabilities for "traditional medicine" services. Issues include determining how to incorporate "traditional" wellness processes into the insurance systems because it is difficult to receive State or Federal reimbursement for traditional healers as there is no way to certify them and there are no reimbursement codes. They questioned whether the determination process could be modified to incorporate traditional medicine and how and who would need to certify traditional healers. One interviewee noted that Cigna PPO reimburses for traditional medicine delivered by Tribally-operated facilities on the Reservation, which might serve as a model. One interviewee requested that the following Statement be included in the report: "Tribally-specific practices need to be recognized and honored."

Tuba City staff were concerned that their recent transition from an IHS-administered system to a contracting facility has raised many questions about how they should administer public benefits programs. However, the staff feels there is nowhere to turn for answers to their questions. In contrast, several interviewees from Service Units that are not currently 638 Tribes noted they are depending on Tuba City and Winslow, which are 638 programs now, to provide recommendations to other Navajo Service Units that will all likely be contracting/compacting with the IHS within the next five years

Several interviewees said they would like an Indian health care delivery system that is comprehensive rather than the currently (in their opinion) fragmented system. As a related concern, several interviewees noted that urban Tribal members have access to urban clinics but not to Tribal facilities, reducing their access to care when residing in urban areas.

According to Navajo Nation interviewees, there was little "Tribal recognition" when Titles XVII, XIV, and XXI were passed. Interviewees also said these outdated Titles should be amended.

Ft. Defiance interviewees said that IHS cannot bill Navajo Nation employee insurance, causing discord in patient incentives for receiving care outside of the IHS system. If IHS refers a patient for care outside of the IHS system, it will pay 100 percent of the costs. In contrast, if a patient with Navajo Nation employee insurance self-refers for care outside of the IHS system, Navajo Nation pays 80 percent of the cost but the patient must pay the other 20 percent coinsurance amount. Additionally, they noted that AI/ANs with Navajo Nation private insurance are not eligible for KidsCare. 58

Ft. Defiance interviewees said that Medicare and IHS database discrepancies with respect to patient identification affects timely reimbursement of Medicare bills.

Another interviewee asked that the following Statement be included in the report: "State regulations do not honor and respect Tribal programs; there is no applicability to each Tribe in each State, reflecting a lack of recognition of Tribal government status at the State level."

#### FINDINGS: TUCSON IHS AREA TRIBES

### Overview

The site visit team attended a group meeting with the Tucson IHS Area director, patient benefit coordinators from San Xavier Health Center and IHS Sells Hospital, the Sells Service Unit director and health systems specialist, a social worker from IHS Sells Hospital, and the administrator of the Pascua Yaqui health program.

According to interviewees, the Tucson IHS Area office and the local Social Security Administration (SSA) office have a good partnership. They said that an SSA worker from the Tucson office visits Sells Hospital once a week to help patients and others in the area to enroll in Medicare. IHS has also worked with the local SSA office to help patients complete Medicare disability applications where interviewees said there is a "lot of need."

The Tucson IHS Area interviewees also reported a very good working relationship with AHCCCS, citing State responsiveness to their requests, including requests for out-stationing of two DES eligibility staff at Sells Hospital and the San Xavier Health Center funded by the State. Local SSA staff and the DES workers often cooperate to provide a place at the hospital and health center that approaches "one-stop shopping." The DES workers have direct access to the AHCCCS system. Interviewees noted that State funding for these positions is important as many poorer rural counties could not afford to pay for out-stationed DES staff. They said that DES and SSA staff, who are often AI/AN themselves, also at times jointly conduct outreach for public benefits programs at the more remote AI/AN villages in the area.

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<sup>&</sup>lt;sup>58</sup> No one who with private health insurance coverage is eligible for KidsCare (CMS comments, July 10, 2003).

<sup>&</sup>lt;sup>59</sup> Interviewees mentioned the El Rio Community Health Center as Tucson's pilot site for uniform/universal application for all State public benefits programs, which is closer to a model of full "one stop shopping." The DES worker at Sells Hospital currently can only conduct medical program screening and eligibility determination but cannot process applications for cash assistance, food stamps, or other State public benefits programs. The El Rio Community Health Center's pilot project, funded by The Robert Wood Johnson Foundation's Covering Kids program, is primarily targeting SCHIP eligibility of Hispanic children in the Tucson area (http://www.coveringkids.org/projects/pilot.php3?PilotID=7, accessed June 22, 2003).

The interviewees emphasized that the State's hiring of an AI/AN liaison for AHCCCS has also been very important for improving State responsiveness to IHS and Tribal facilities and for increasing AI/AN enrollment in AHCCCS and KidsCare. Having a single, identified State staff to work with has noticeably improved the IHS/State partnership.

Sells Hospital staff said it attends all Tucson district meetings for IHS presentations. Sells staff feels it has a good system within the hospital for processing Medicaid, SCHIP, and Medicare applications. Due to DES out-stationing and outreach, State assistance, and a good screening and application assistance program within the hospital and health centers, interviewees estimated that about 50 percent of funds for patient care in the Sells Service Unit is derived from third-party billing.

### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

According to Tucson IHS Area interviewees, under-enrollment of AI/ANs in AHCCCS and KidsCare in their area is a minor problem. They believe that most AI/ANs are aware of the programs. Several reasons that under-enrollment is not a bigger problem is that DES eligibility workers are assigned to each AI/AN village and visit each village on a monthly basis to enroll eligible persons in AHCCCS and KidsCare. Additionally, PBCs and DES out-stationed eligibility workers at the IHS hospital and health centers are available to assist with applications. They also said that legal assistance is often available if needed for appealing program denials.

The interviewees estimate that non-IHS facility users comprise the largest group of under-enrolled in all of the programs. Another under-enrolled group consists of AI/ANs who do not apply for State cash assistance programs. According to interviewees, people who need cash assistance are more likely than those only interested in AHCCCS or KidsCare to apply for the programs at the same time they apply for cash assistance. The former group is also more likely to renew health program enrollment, again at the same time as they re-certify for cash assistance programs.

According to interviewees, another "pocket" of under-enrolled AI/ANs are members of the Oklahoma Kickapoo Tribe residing in Douglas, Arizona and Mexico. Interviewees noted that IHS and the State have recently begun to work with Tribal leaders and local community centers to enroll Kickapoo members in AHCCCS.

#### Barriers to Initial Enrollment

According to the interviewees, once the AHCCCS or KidsCare enrollment process is started, it generally runs smoothly. Also, the joint AHCCCS/KidsCare application ensures that applicants apply for the program that is most appropriate to their situation. The most difficult step is getting people to start the process. Although under-enrollment is fairly low, interviewees said a few barriers still exist that if eliminated could further increase program enrollment:

• Some AI/ANs do not realize they might qualify for AHCCCS or KidsCare coverage. In particular, parents who work and those with private health insurance may think their

incomes are too high.<sup>60</sup> The interviewees perceive that not many AI/ANs in their area are eligible for KidsCare because low incomes instead make them eligible for AHCCCS.

- Transportation to a DES office to obtain in-person application assistance may be an issue for some AI/ANs, particularly in the more remote isolated AI/AN villages. However, PBCs did not perceive that transportation issues are a significant barrier for most AI/ANs in the Tucson area because the Tohono O'odham Tribe provides limited transportation to DES offices and medical services and the State's SafeRide program is available to transport AHCCCS enrollees to providers.
- Documentation, including birth and marriage certificates, for an application might be either unavailable or difficult to obtain.
- In the Sells Service Unit, distances are too great for PBCs to be able to conduct outreach outside of the hospital, with insufficient staff to reach isolated rural areas.
- AI/ANs are comfortable with the IHS system but "fear" the AHCCCS and KidsCare systems because they do not understand them, as well as having a general wariness of government programs and non-IHS providers.

## Barriers to Maintaining Enrollment

Interviewees do not believe that redetermination problems are an issue for Tucson-area AI/ANs. The State notifies AHCCCS, KidsCare, and Medicare Savings Programs recipients by mail a month before redetermination is due. The letter is sent in both English and Spanish and provides a Statewide toll-free telephone number for additional information about redetermination letters or processes. According to the interviewees, the State tries to give clients a lot of information about redetermination upon initial program enrollment. Additionally, the AHCCCS system allows PBCs to identify AI/ANs dropped from the program.

Interviewees noted that persons who do not think they will need services in the near future are less likely than others to re-certify as they may not see a continuing need for AHCCCS or KidsCare benefits.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

According to Tucson IHS Area interviewees, under-enrollment of AI/ANs in Medicare Part A in the area is only a minor problem, but there is substantial under-enrollment in Medicare Part B.

They believe that under-enrollment in the Medicare Savings Programs is not a large problem because PBCs at IHS facilities work closely with the Tucson SSA office, which refers potentially-eligible AI/AN clients to PBCs for application assistance.

<sup>&</sup>lt;sup>60</sup> Children who currently have private insurance coverage from their parents' employment are NOT eligible for KidsCare or AHCCCS (information provided by CMS, July 2003).

Interviewees asserted that non-IHS facility users are likely to comprise the largest group of under-enrolled in all of the programs.

The large under-enrollment in Medicare Part B and some under-enrollment in the Medicare Savings Programs are caused by the following enrollment obstacles, according to those interviewed:

- Elders often only become aware of, or see the need to enroll in, Medicare Part B or the Medicare Savings Programs when they are seriously ill and have no alternatives. They often do not become aware of the programs or procrastinate applying until there is a crisis.
- Some AI/ANs are dropped from Medicare Part B for failure to pay the premium. They then have to pay extra if they try to re-enroll in a crisis, which may be difficult.
- AI/ANs may be aware that the programs exist, but many need more education about the benefits of the programs, how benefits and access to services interact between Medicaid and IHS, and which benefits the various programs cover.
- Some AI/ANs feel it is their right to be covered by Contract Health Services funds whether or not they have first applied for other third-party insurance because of the perceived Federal Trust Responsibility to provide AI/ANs with health care.
- Increasingly fewer providers in the Tucson area are willing to treat Medicare patients due to low Medicare payment rates. This reduces incentives for IHS to enroll AI/ANs and often makes it difficult for IHS to locate services for CHS-referred patients.
- According to interviewees, disabled persons who apply for Medicare are usually denied the first time they apply. This discourages many from re-applying even though the PBCs tell patients to apply again because some are accepted on subsequent attempts.

## Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

Interviewees noted their strong belief that the AI/AN liaison at the State level has been very important to increasing enrollment. Tucson IHS Area staff also meets with State health directors on a regular basis, citing this as important for facilitating Tribal, IHS, and State communications and increasing AI/AN program enrollment. IHS staff is also part of a State-facilitated health care coalition organized by the State and IHS that meets every other month to share information. IHS regularly makes presentations to Tribal councils and patient advisory committees to explain how third-party resources benefit them, why application questions are being asked, and to note new health care services that are a direct result of third-party revenues (e.g., dental services). The Tucson IHS staff also publicizes new health care projects and improvements through flyers and articles in local and Tribal newspapers.

In addition to the many positive activities that currently help them to increase and maintain Tucson area AI/AN enrollment in the AHCCCS, KidsCare, and Medicare programs, the interviewees provided several additional recommendations:

- Provide increased program education for Tribal leadership and Tribal communities. Interviewees said that they do not feel they have had much Tribal council support for their outreach activities because Tribal leadership is concerned that if IHS facilities encourage the use of alternative resources, IHS funding will decline proportionately. Interviewees suggested that education is needed to inform Tribal leadership and Tribal communities of the importance of third-party revenues, eligibility guidelines, and benefits available through the public insurance programs.
- Suggestions from interviewees included distributing educational pamphlets and flyers where "there's a high flow of traffic, such as at District Centers," running radio, 61 television, and local newspaper public service announcements, placing articles in Tribal newsletters (e.g., the Papago Runner), and conducting home visits. All printed material should at most be at an eighth grade reading level. Interviewees also emphasized that all outreach strategies and materials need to be developed by, and for, local communities. 62
- Consumer messages should be framed in terms of Tribal values and value systems, designed around issues that people gauge important to their lives and how medical illness is defined in Tribal traditions.
- **Develop a resource center at each IHS facility**. Interviewees recommended development of a resource center at each IHS facility that would include State, CMS, and SSA workers for "one-stop shopping," and that would also include local paid trained outreach workers.
- **Provide funds to hire additional Patient Benefit Coordinators**. The Tucson IHS Area interviewees said they need one or two additional PBCs who are Tribal members to identify client eligibility for various programs, provide application assistance, explain programs to patients, follow-up with patients who fail to re-certify, and make home visits with AI/ANs who are elderly, handicapped, and/or have no available transportation.
- Include a local contact person on the State's redetermination letter. Interviewees said many AI/ANs may feel more comfortable contacting a local instead of a State person.
- State allow PBCs to determine eligibility on-site (although interviewees noted that there could be legal issues with this approach). AI/ANs are more comfortable with the IHS system; additionally, this approach would acknowledge Tribal sovereignty issues. In any case, PBCs need to be formally certified and trained on AHCCCS and KidsCare application completion and documentation requirements to facilitate smoother and faster eligibility determinations after DES receives an application.

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<sup>&</sup>lt;sup>61</sup> PBCs noted that Sells community would benefit from having a local radio station that could be used to advertise public benefits programs.

<sup>&</sup>lt;sup>62</sup> PBCs said they heard that the Tucson SSA is planning on producing a video that includes Tohono O'odham-speaking people that would describe eligibility guidelines for Medicare, the Medicare Savings Programs, Social Security Income, and other programs of interest to elderly persons. They strongly support this idea.

- AHCCCS and KidsCare health plan staff, DES eligibility workers, and SSA staff attend Tucson district meetings. PBC interviewees said that this would allow all to regularly share information about program eligibility, changes in the programs, etc.
- State, IHS, and CMS provide technical assistance. Pascua Yaqui representatives said they would like technical assistance from the State, IHS, and CMS to develop a program that would help them to identify alternate resources because their current IHS resources do not meet Tribal members' health care needs.

### Other Issues

Interviewees said that Tucson Tribal proximity to the Mexico border leads to unique problems. They said that undocumented non-AI/AN aliens and Tucson area Tribal members who are non-U.S. citizens are a big issue at Sells Hospital. Their understanding is that the State pays for emergency health care services only for AI/ANs (and others) who intend to reside permanently in Arizona. State funds cannot be used to pay for emergency services for people who cross back and forth over the border. However, under Federal law, the hospital cannot deny emergency services to anyone. They said that IHS does not provide funding to Sells Unit facilities to provide services to these people. Although the hospital receives some funds from the Immigration and Naturalization Service to provide care to non-U.S. citizens, the interviewees said it is not enough to cover their needs. They noted that this problem affects all border hospitals (public and private), forcing some to close.

Interviewees also noted that IHS and Tribal facilities cannot bill Medicaid, Medicare, or SCHIP programs or private insurance sources for "traditional medicine." But they also noted there are pros and cons, as well as potential legal issues, to government involvement with the provision of traditional medicine services. Therefore, interviewees expressed uncertainty whether or not they would recommend government payment for such services.

#### FINDINGS: URBAN INDIAN HEALTH CENTERS

#### **Tucson Indian Center**

### Overview

At the time of our site visit to Tucson, the Tucson Indian Center had only recently become the IHS-contractor for the Urban Indian Health Program (under Title V of the Indian Health Care Improvement Act, PL 94-437 as amended) for the Tucson area. We met in-person with the Center's Executive Director, Wellness Director, and Wellness Coordinator. We also conducted a follow-up telephone interview in late January 2003 with the Center's Wellness Director.

<sup>&</sup>lt;sup>63</sup> According to an AI/AN consultant to this project, however, IHS appropriated funds can legally be spent for AI/ANs whether or not they are U.S. citizens. This includes emergency and non-emergency services. It is not clear, though, whether an IHS facility can bill Medicaid for providing services to non-AI/AN illegal aliens because the facility cannot spend funds for a non-appropriated purpose and subsequently recover costs from a State Medicaid agency. The issue is very complicated, but is beyond the scope of this project, which focuses on public insurance program enrollment barriers.

As a new urban Indian program, IHS has provided funding for it to perform two area health needs assessments for the Tucson urban AI/AN population and the Tohono O'odham Tribe in the Sells Service Unit. During their assessments, staff will also inquire about SCHIP eligibility and enrollment, which is a part of the study also funded by IHS.

## Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Tucson Indian Center interviewees believe that most of their clients are aware of the AHCCCS and KidsCare programs, and they do not believe that under-enrollment is a large problem in their area. However, they said that their clients often do not know how to access care through these programs due to a lack of understanding about how to navigate among the IHS, urban health, and private health care systems. They also noted that although awareness of KidsCare appears to be high, under-enrollment in this program is likely to be greater than in AHCCCS due to misunderstanding of eligibility criteria (e.g., some AI/ANs believe their income is too high to qualify).

- Interviewees largely credit low program under-enrollment of AI/ANs living in the Tucson urban area to the close proximity of the San Xavier Health Center on the Tohono O'odham Reservation. They said San Xavier Health Center's staff, as well as staff at other IHS facilities in the Tucson IHS Area, try to maximize third-party reimbursements by ensuring that all of their eligible patients are enrolled in health insurance programs. Although transportation to IHS facilities can pose a barrier to AI/ANs living in the Tucson urban area (one reason is that the city bus does not go to any IHS facilities on the nearby Reservations), the Tucson Indian Center, as well as several other community-based organizations that serve AI/ANs in Tucson, provide regularly-scheduled transportation to several of these facilities including the San Xavier Health Center.
- Interviewees noted that some AI/ANs in the Tucson urban area do not have a birth certificate, which is required for program application. Because of this, they also are not able to provide proof of citizenship, receive a passport, obtain care at Veterans Administration health facilities, or access other programs. Interviewees noted this is not a frequent occurrence for AI/ANs residing in the Tucson urban area, but is a much bigger problem for AI/ANs living on the Tohono O'odham and other nearby Reservations.

### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Tucson Indian Center interviewees believe that most of their clients are aware of the Medicare and Medicare Savings Programs, and they do not believe that under-enrollment is a large problem in their area. Interviewees cited the same area activities noted in the previous section as being responsible for relatively high enrollment in these programs, as well as cited the same barriers that prevent 100 percent enrollment of all eligible urban Indian AI/ANs in the programs.

## Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

- The Tucson Indian Center staff attempts to ensure that clients know which programs are available to them, including private insurance coverage. Case managers at the Center help clients complete applications if requested. Additionally, the Center provides bus passes to clients to the local DES office to apply for AHCCCS or KidsCare. They also refer clients to AHCCCS providers if either a client cannot find transportation to a nearby IHS facility that provides the needed services or if the services are unavailable at a nearby IHS facility. The Tucson Indian Center does not provide short-term child care services to assist clients with visiting a DES office, and, while it has no legal staff, the Center does refer AI/ANs with program denials or other problems to intern law clinics at the University of Arizona to provide limited legal assistance.
- Additional funding from IHS, the State, and CMS to help them develop educational program outreach and hire more outreach workers. Interviewees said there is a perception among urban AI/ANs that "all health care must come through IHS; if IHS facilities are not available, then the health services are not available." To date, the Center's educational activities have focused on supporting the IHS model/facilities, but the Center is expanding and would like to become a community health center with IHS viewed as only one health care resource. Interviewees also said that the Center is planning to conduct more AHCCCS, KidsCare, and Medicare outreach through their existing community-based education activities for the Center's other programs. Interviewees said that additional funding from IHS, the State, and CMS to help them develop educational program outreach and hire more outreach workers would significantly improve their ability to do this.
- Lack of birth certificates. Regarding the lack of birth certificates for some AI/ANs, interviewees said that area Tribes are currently working with the State to resolve the problem but did not think they had yet found a solution.

### **Phoenix Indian Medical Center**

### Overview

Following the site visit, the site visit team held a telephone interview with the senior Patient Benefits Coordinator at the Phoenix Indian Medical Center (PIMC). PIMC is the largest of the nine IHS-funded hospitals serving the Phoenix IHS Area. In addition to serving Phoenix urban area AI/ANs, patients are referred there for specialized care not available at Arizona's AI/AN Reservation hospitals.

### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

The interviewee believes there is substantial AI/AN under-enrollment in the AHCCCS and KidsCare in the Phoenix Service Unit, both those living in urban areas and on Reservations. She reported that PBCs at the hospital have observed the following barriers to area AI/AN enrollment in these programs:

- There is high awareness of AHCCCS programs but low awareness of the KidsCare program, perhaps because it is a relatively new program and has not been heavily publicized.
- Although most AHCCCS programs and the KidsCare program do not require in-person application at a local DES office, many AI/ANs in the area do not realize this. Reliable transportation to a DES office often presents an obstacle to application.
- The PBC said the AHCCCS application process is "cumbersome," primarily because of the amount of documentation that must accompany the application. PIMC patients have also reported that there is a long wait for an appointment at the local DES office, and that DES staff has lost applications because of their extremely high workloads.
- Another enrollment barrier PBCs often experience is that AI/ANs in the Phoenix urban area have access to IHS facilities so they do not see the need for third-party health insurance. She said many apply for insurance programs only when they are in a crisis mode after discovering neither they nor the IHS can pay for or provide health care services needed or already received.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

The interviewee believes there is large under-enrollment in Medicare Part A and Part B among AI/ANs in the Phoenix Service Unit. She estimates that about one-half of PIMC's patients are unaware of the Medicare program or are unaware that they "need to call or visit the Social Security office to enroll."

Barriers to Medicare enrollment include a substantial lack of telephones and reliable transportation services on area Reservations. Additionally, she said that, even for AI/ANs who know that the Medicare program exists, many do not believe it is available to them because they believe they can receive all of the services they need through IHS facilities.

## Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

The PBCs at PIMC screen all patients upon admission for third-party health insurance eligibility, paying particular attention to patients age 65 or older. In March, when a Social Security representative is on site for several days (as requested by PIMC), PBCs work with the representative to identify and enroll eligible elderly patients in Medicare Parts A and B and the Medicare Savings Programs. Even if a patient currently has Medicare Part B, PBCs will screen for Medicare Savings Programs eligibility. The interviewee said that the PBCs find that "quite a few" AI/AN elderly patients are eligible for the Medicare Savings Programs. PIMC staff either assists with application completion on site or mails an application if the patient did not receive in-person assistance at the hospital.

At the hospital's request to the State, two State-sponsored DES workers are currently outstationed at PIMC. According to the PBC interviewed, the out-stationing has increased AHCCCS enrollment significantly among the hospital's inpatients (the DES workers only process

applications for inpatients). PBCs provide application assistance for outpatients as described above.

The PBC provided the following recommendations for further increasing program enrollment among Phoenix IHS Area AI/ANs:

- Increased State outreach, particularly for KidsCare. At one time it played radio public service announcements, which seemed to be effective according to the interviewee. The State also displayed posters and attended health fairs, but less of this type of outreach occurs now. She suggested the State could place KidsCare posters that include AI/AN pictures and symbols in IHS hospitals and display them at community health fairs, as well as establish a day in the hospital a few times a year (as funds permit) to raise program awareness.
- **Increased program training for PBCs**. Most PBCs at PIMC must learn Medicaid, SCHIP, Medicare, and other State benefits program details on their own. The State provided limited training through the Baby Arizona program, but she said much more is needed. Increased training funds could come from the States, IHS, and/or CMS.
- Increased State funding for PIMC to hire outreach workers. Outreach workers are both needed on-site and to go to people's homes to help with application assistance so AI/ANs living in either the urban area or on Reservations do not need to go to a DES office.
- Enable PBCs to search the AHCCCS system for current applicant status. Through PIMC's access to the State's AHCCCS computer system, PBCs receive notice when a patient is approved for a program but are not allowed to search the system for current application status. She said PBCs at the hospital call DES offices daily to check on pending applications; however, it is hard for DES to verify application status and DES staff communications are often poor. It would greatly help PBCs to be able to search the AHCCCS system for current applicant status for PIMC patients.
- Provide AHCCCS funding for transportation services, such as SafeRide Services, to DES offices. The interviewee believes this would increase incentives for AI/ANs to enroll in the AHCCCS and KidsCare programs.

## **DISCUSSION**

There was considerable agreement among interviewees – the State, those living in Tribal areas of Arizona, and those located in urban areas – that AI/AN under-enrollment in AHCCCS

<sup>&</sup>lt;sup>64</sup> Baby Arizona, a public/private initiative to increase the number of Arizona women who receive early and continuous prenatal care, is managed by AHCCCS. Baby Arizona's Statewide, comprehensive approach to outreach, education, and coordination of services has four major components: a Statewide hotline for information and referral of pregnant women; application for medical assistance through health care providers; support of community-based programs with informational materials and technical assistance/support for identifying areas for new community initiatives; and a public awareness campaign (http://www.azwellness.com/babyarizona.html, accessed May 19, 2003).

should not be characterized as a serious problem, but only as a "moderate" or "minor" one (particularly in the Tucson Tribal and urban areas). The exception was the Phoenix Indian Medical Center interviewee's perception that there is substantial under-enrollment in the AHCCCS (and KidsCare) program among AI/ANs in the Phoenix Service Unit, for both AI/ANs living in urban and Reservation areas. Except in Phoenix, program enrollment success among AI/ANs in the State was often credited to successful out-stationing of DES eligibility workers at many sites across the State and the efforts of PBCs at IHS hospital and health centers to assist with the application process.

Navajo interviewees reported that Tribal under-enrollment in New Mexico's Medicaid program is not a serious problem; however – particularly in the Service Unit closest to the Utah border (Kayenta) – they face significant challenges in enrolling AI/ANs in Utah's Medicaid program.

There was also considerable agreement that KidsCare under-enrollment and redetermination issues, though not substantial in most areas of Arizona, are more prevalent than for AHCCCS programs. Interviewees at several sites commented that most people who receive AHCCCS also receive food stamps and State cash assistance, for which they apply simultaneously and in person. In contrast, KidsCare is a "stand-alone" program for most recipients with redetermination accomplished primarily through the mail. This difference accounts for some of the AI/AN under-enrollment differences between the two programs. Interviewees from several NAIHS Service Units believe there is serious under-enrollment in both Arizona's and New Mexico's SCHIP programs and noted that Utah has capped SCHIP enrollment. The higher AI/AN under-enrollment in KidsCare was also attributed to it being a new program that has not been well publicized and that is not viewed as an option for most AI/ANs who think their incomes are either too low or too high to qualify.

Although the AHCCCS Native American Coordinator estimated that a "sizeable number" of AI/ANs in Arizona do not qualify for Medicare Part A due to insufficient work history, as well as there being many AI/AN widows who do not realize they are eligible under their spouse's work history, other interviewees estimated minor under-enrollment in Medicare Part A. However, all agreed that elders generally either do not realize that they have this coverage or do not understand their benefits and how the program works. Again, the exception was the PIMC PBC, who believes there is large under-enrollment in Medicare Part A and Part B among AI/ANs in the Phoenix Service Unit. Kayenta Service Unit interviewees also stated that Medicare under-enrollment is a relatively serious problem for Navajos in their area. Kayenta interviewees said Navajos in their area are significantly under-enrolled in both Medicare Parts A and B and the Medicare Savings Programs. They attributed this mainly to the fact that "Tribal members tend to look to IHS to help with everything."

In contrast to Medicare Part A, there was general agreement among most interviewees that there is substantial under-enrollment in Medicare Part B and the Medicare Savings Programs among Arizona AI/ANs. An exception was the AHCCCS Native American Coordinator who said that until a couple of years ago, AI/AN under-enrollment in the Medicare Savings Programs was a serious problem but would characterize it as a moderate problem currently. She mainly attributes the turn-around to the success that the ITCA AAA has had with conducting public

assistance outreach to AI/AN Tribes in Arizona through a Federal grant. ITCA interviewees, however, believe that under-enrollment of Arizona Tribal members in the Medicare Savings Programs is still a serious problem. Another exception is Tucson area interviewees, who believe that under-enrollment in the Medicare Savings Programs is not a large problem because PBCs at IHS facilities work closely with the Tucson SSA office, which refers AI/AN clients to the PBCs for application assistance if they appear eligible.

There was unanimous agreement among persons interviewed in Arizona that non-IHS/Tribal facility users likely comprise the largest group of under-enrolled in all of the programs. Additionally, the non-user populations located in the more isolated, rural areas are more likely to be under-enrolled. Because there is little or no outreach to non-patients in most of the State, and uninsured people are only screened when they present at health facilities, "healthier" eligible AI/ANs and those living in rural areas (which are hardest to reach) are most likely to be under-enrolled in Medicaid, SCHIP, and Medicare. Interviewees, however, said that AI/ANs in the Phoenix and Tucson urban areas generally have access not only to urban Indian programs, but also to IHS/Tribal facilities, receiving similar enrollment assistance as AI/ANs residing in Reservation areas and facing similar under-enrollment rates.

Another under-enrolled group mentioned by several interviewees consists of AI/ANs who do not apply for State cash assistance programs. According to Tucson interviewees, another "pocket" of under-enrolled AI/ANs are members of the Oklahoma Kickapoo Tribe residing in Douglas, Arizona and Mexico. Interviewees noted, however, that IHS and the State have recently begun to work with Tribal leaders and local community centers to enroll Kickapoo members in AHCCCS.

Those interviewed across the State provided numerous reasons for under-enrollment in AHCCCS, KidsCare, Medicare, and the Medicare Savings Programs in Arizona. However, several were cited by all of those interviewed as being significant enrollment barriers for AI/AN. These include:

- Lack of AI/AN consumer understanding about the benefits of the different programs and
  why they should enroll when they have access to IHS facilities many only enroll when
  faced with a crisis and no alternatives to receiving or paying for needed health care
  services.
- Too few PBCs available to provide in-person consumer education and application assistance, as well as too little intermediary training about all of the public insurance programs.
- Lack of AI/AN consumer knowledge about how Medicare, AHCCCS, and KidsCare programs coordinate with IHS/Tribal health services, and lack of knowledge on the part of many AI/ANs about how to use health insurance or access health services outside of the IHS/Tribal health care system.
- Illiteracy and language issues.
- Lack of transportation and communication infrastructure on Reservation lands.

• Application process difficulties, particularly related to acquiring needed documentation, most notably birth and marriage certificates.

Because the Navajo Reservation spans three States, Navajo interviewees cited additional barriers to the above that prevent many Navajos from enrolling in Medicaid, SCHIP, and the Medicare programs:

- The need to understand, communicate with, and coordinate benefits among three different State Medicaid programs and three different CMS regions.
- Little Tribal government-to-government relationship with the State of Utah.
- Lack of infrastructure on the Navajo Reservation for training, program development, and information sharing.
- Lack of a true government-to-government relationship between Navajo Nation and the U.S. government that filters down to the County level. Staff reported a poor relationship between the Tribe and County governments within the Reservation.
- Navajo Nation's agreement with Arizona's Division of Child Support Enforcement deters many potential beneficiaries from enrolling in Medicaid and KidsCare.

Mirroring the most common and significant barriers to program enrollment, the majority of persons interviewed in Arizona recommended similar strategies for increasing enrollment in Medicaid, SCHIP, and Medicare. These included additional consumer and community education, particularly for KidsCare in Arizona; additional funding to hire PBCs and other outreach workers; and consistent, regular, comprehensive cross-training for all possible intermediaries who might come in contact with program-eligible AI/ANs. Other common recommendations encompassed cross-training for State and Federal agency staff who work with these programs, and "one-stop shopping" ideas including increased out-stationing of DES workers at IHS and Tribal facilities and other Tribal sites. Suggestions also included developing a clearinghouse for program information (ITCA was mentioned as a possible grantee for this role), and calls from several interviewees for additional training and technical assistance to permit greater Tribal use of computers for third-party billing purposes and Internet access.

Navajo interviewees also recommended the above strategies for increasing program enrollment. However, because of their unique situation, they also discussed the possibility and advantages of creating a Tri-State Medicaid agency for Navajo Nation. Additionally, considerable discussion focused on the great need for increased collaboration and partnerships in their area. They said there is a need for on-going, regular communications among State, Federal, and County agencies, Tribal health facility staff, Tribal social services staff, and others who work on a daily basis with low income Tribal members Many of those interviewed at the Service Units suggested that a "bottom-up approach" might work best, in which front-line workers cooperatively develop recommendations through workgroups to solve global problems and bring these recommendations to "decision makers" to implement.

Interviewees generally agreed that visual and oral consumer education methods, such as videos and perhaps radio and television, are much more likely to be effective for reaching AI/ANs than printed materials. Also, outreach strategies and methods should be designed and implemented by local AI/AN communities and not by State or Federal agencies, and should rely on existing Tribal infrastructures to identify potential applicants. As well, there was unanimous agreement that in-person consumer education and assistance is needed for the majority of AI/ANs in the State to enroll in the public insurance programs.

Several interviewees, including the AHCCCS/KidsCare Native American Coordinator, noted the decrease in State-funded AHCCCS and particularly, KidsCare, outreach among AI/ANs due to State budget cuts. For example, the Native American Coordinator said that the State formerly funded "outreach contractors," which she believes made some inroads into increasing AHCCCS and KidsCare enrollment among AI/ANs. However, these positions are no longer funded.

# APPENDIX III.A: ARIZONA SITE VISIT CONTACT LIST

# Arizona Health Care Cost Containment System (AHCCCS)/KidsCare Programs

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## **Inter Tribal Council of Arizona**

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Gilbert Patino	Specialist, National Family Caregiver Support Program	Inter Tribal Council of Arizona, Inc., 2214 North Central Avenue, Suite 100, Phoenix, AZ 85004	602-258-4822	gilbert.patino@itcaonline.com
Victoria Spencer	Specialist, Public Benefit Outreach Project	Inter Tribal Council of Arizona, Inc., 2214 North Central Avenue, Suite 100, Phoenix, AZ 85004	Not Available	Not Available

# Navajo State Health Insurance Assistance Program (SHIP)

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# Navajo Area Indian Health Service

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	Navajo Area IHS	86515-9020		
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# Navajo Nation

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Vernita Halwood	Contract health Representative /Patient Benefits Coordinator, Chinle Hospital	Navajo Nation, Chinle Service Unit, Chinle Comprehensive Health Care Facility, P.O. Box Drawer PH, Chinle, AZ 86503	928-674-7001	Not Available

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Public Service Evaluator, Chinle Hospital	Navajo Nation, Chinle Service Unit, Chinle Comprehensive Health Care Facility, P.O. Box Drawer PH, Chinle, AZ 86503	928-674-7001	Not Available
Navajo Regional Behavioral Health Authority, Chinle Hospital	Navajo Nation, Chinle Service Unit, Chinle Comprehensive Health Care Facility, P.O. Box Drawer PH, Chinle, AZ 86503	928-674-7001	Not Available
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Patient Benefits Coordinator, Gallup Indian Medical Center	Gallup Indian Medical Center, P.O. Box 1337, 515 E. Nizhoni Bovd., Gallup, NM 87305	505-722- 1000	Not Available
ce Unit	I	T	
Contract Health Services, Kayenta Health	Kayenta Service Unit, P.O. box 368, Kayenta, AZ 86033	928-697- 4000	Not Available
	Evaluator, Chinle Hospital  Navajo Regional Behavioral Health Authority, Chinle Hospital  Service Unit Chief Nurse Executive, Ft. Defiance Hospital Chief Executive Officer, Ft. Defiance Hospital Business Manager, Ft. Defiance Hospital Patient Registration and Patient Benefits Coordinator, Ft. Defiance Hospital  Ft. Defiance Hospital  Contract Health Services, Ft. Defiance Hospital  Contract Health Services, Ft. Defiance Foordinator, Gallup Indian Medical Center Patient Benefits Coordinator, Gallup Indian Medical Center  The Contract Health Contract Health Contract Health Coordinator, Gallup Indian Medical Center  The Contract Health Contract Health Coordinator, Coordinator, Coordinator, Coordinator, Coordinator, Coordinator, Coordinator Coo	Public Service Evaluator, Chinle Hospital  Navajo Regional Behavioral Health Care Facility, P.O. Box Drawer PH, Chinle, AZ 86503  Navajo Nation, Chinle Service Unit, Chinle Comprehensive Health Care Facility, P.O. Box Drawer PH, Chinle, AZ 86503  Navajo Nation, Chinle Service Unit, Chinle Comprehensive Health Care Facility, P.O. Box Drawer PH, Chinle, AZ 86503  Service Unit  Chief Nurse Executive, Ft. Defiance Hospital  Chief Executive Officer, Ft. Defiance Hospital  Business Manager, Ft. Defiance Hospital  Patient Registration and Patient Benefits Coordinator, Ft. Defiance Hospital  Fort Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital  Fort Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital  Fort Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86	Public Service Evaluator, Chinle Hospital  Navajo Regional Behavioral Health Care Facility, P.O. Box Drawer PH, Chinle, AZ 86503  Navajo Navajo Nation, Chinle Service Unit, Chinle Comprehensive Health Care Facility, P.O. Box Drawer PH, Chinle, AZ 86503  Navajo Nation, Chinle Service Unit, Chinle Comprehensive Health Care Facility, P.O. Box Drawer PH, Chinle, AZ 86503  Service Unit  Chief Nurse Executive, Pt. Defiance Hospital  Chief Executive Officer, Ft. Defiance Hospital  Chief Executive Officer, Ft. Defiance Hospital  Business Manager, Ft. Defiance Hospital  Patient Registration and Patient Benefits Coordinator, Ft. Defiance Hospital  Fort Defiance Hospital, P.O. Box 649, Ft. Defiance Hospital P.O. Box 649, Ft. Defiance, Arizona 86504  Contract Health Services, Ft. Defiance Hospital  Fort Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Fort Defiance Hospital, P.O. Box 649, Ft. Defiance, Arizona 86504  Gallup Indian Medical Center Patient Benefits Coordinator, Gallup Indian Medical Center  Patient Benefits Coordinator, Gallup Indian Medical Center  Patient Benefits Coordinator, Gallup Indian Medical Center  Patient Benefits Coordinator, Gallup Indian Medical Center  Patient Benefits Coordinator, Gallup Indian Medical Center  Patient Benefits Coordinator, Gallup Indian Medical Center  Patient Benefits Coordinator, Gallup Indian Medical Center  Po. Box 1337, 515 E. Nizhoni Bovd., Gallup Indian Medical Center  Patient Benefits Coordinator, Gallup Indian Medical Center  Po. Box 1337, 515 E. Nizhoni Bovd., Gallup Indian Medical Center  Po. Box 1337, 515 E. Nizhoni Bovd., Gallup Indian Medical Center  Po. Bo

	Center			
Brenda Brown	Monument Valley Health Center	Monument Valley Health Center, P.O. Box 360-05, Monument Valley, AZ 84536	435-727- 3241	Not Available
Marty Bronston	Patient Benefits Coordinator, Kayenta Health Center	Kayenta Service Unit, P.O. box 368, Kayenta, AZ 86033	928-697- 4000	Not Available
Annaletta Austin	Patient Advocate, Kayenta Health Center	Kayenta Service Unit, P.O. box 368, Kayenta, AZ 86033	928-697- 4000	Not Available
Shirlee Bedonie	Medicaid Eligibility Specialist, State of Utah Division of Healthcare Financing	Monument Valley Health Center, P.O. Box 360-05, Monument Valley, AZ 84536	435-727- 3230	shirleeabedonie@utah.gov
Avis Singer	Patient Registration, Kayenta Health Center	Kayenta Service Unit, P.O. box 368, Kayenta, AZ 86033	928-697- 4000	Not Available
Derrick Kay	Contract Health Services/Billing, Kayenta Health Center	Kayenta Service Unit, P.O. box 368, Kayenta, AZ 86033	928-697- 4000	Not Available
Michelle Isone	Patients Benefits Coordinator, Inscription House Health Center	Inscripition House Health Center, P.O. Box 7397, Tonalea, AZ 86044	520-672- 2611	Not Available

Tuba City Serv	ice Unit			
Joe Hinez	Patients Benefits Coordinator, Tuba City Regional Hospital	Tuba City Indian Hospital, 167 N. Main St., P.O. Box 600, Tuba City, AZ 86045	928-283-2683	Not Available
Victor Hanel	Patients Benefits Coordinator, Tuba City Regional Hospital	Tuba City Indian Hospital, 167 N. Main St., P.O. Box 600, Tuba City, AZ 86045	928-283-2501	Not Available
Patty Galst	Business Office Manager, Tuba City Regional Hospital	Tuba City Indian Hospital, 167 N. Main St., P.O. Box 600, Tuba City, AZ 86045	928-283-2501	Not Available
Susan Penberry	Contract Health Services, Tuba City Regional Hospital	Tuba City Indian Hospital, 167 N. Main St., P.O. Box 600, Tuba City, AZ 86045	928-283-2501	Not Available
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Patti Whitethorn	Administration Tuba City Regional Hospital	Tuba City Indian Hospital, 167 N. Main St., P.O. Box 600, Tuba City, AZ 86045	928-283-2829	Not Available
Winslow Servic	re Unit			
Mae-Gilene Begay	Navajo Division of Health	Winslow Health Center, 619 E 3rd, Winslow, AZ 86047	520-289-4646	Not Available

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Maxine Nakai	Clinical Specialist	Navajo Nation Regional Health Authority, P.O.Box Drawer 709, Window Rock, AZ 86515	928-871- 6877	Not Available	
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Mandel Pendel	Navajo Regional Behavioral Health Authority	Navajo Nation Regional Health Authority, P.O.Box Drawer 709, Window Rock, AZ 86515	928-871- 6355	Not Available	
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### **CHAPTER IV. MICHIGAN**

#### **BACKGROUND**

#### Overview

This Case Study Report presents background information and findings from a three-day site visit to Michigan conducted from October 14 to October 16, 2002. The site visit team consisted of Sally Crelia (Site Coordinator) and Erika Melman of BearingPoint, and Rebecca Baca of Elder Voices, project consultant. The team visited the Sault Ste. Marie Tribe of Chippewa Indians in Sault Ste. Marie, Michigan, the Grand Traverse Band of Ottawa and Chippewa Indians in Suttons Bay, Michigan, and the American Indian Health and Family Services of South East Michigan in Detroit, Michigan, conducting interviews with individuals and groups in each location. The rationale for selecting the sites visited and description of the sites is provided in the following section.

An earlier version of this Case Study Report was reviewed by the CMS Project Officer and other CMS staff for accuracy and clarity. Subsequently, a Draft Case Study Report was sent to each of the Michigan organizations that participated in the site visit, with a request that the draft be reviewed for accuracy and notification that comments and additions would be incorporated into the Case Study Report. Follow-up telephone contacts were made with all of these organizations. Comments and corrections were received from all of the organizations interviewed and are incorporated into this report.

The comments and recommendations contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or the feasibility of the recommendations. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services (CMS), the Indian Health Service (IHS), or the State.

## Michigan AI/AN Population and Location

The AI/AN population of Michigan is proportionally one of the largest among States east of the Mississippi River. Approximately 70,194 AI/ANs live in Michigan (identified as AI/AN race alone on the U.S. Census), representing 0.7 percent of the State's total population. 65 Michigan has 12 Federally Recognized Tribes. 66 Historically, the three major Tribes in Michigan have been the Chippewa, Ottawa and Potawatomi. 67 Over 42 percent of the AI/AN population

<sup>&</sup>lt;sup>65</sup> Urban Institute and the Kaiser Commission on Medicaid and the Uninsured, estimates based on pooled March 2001 and 2002 Current Population Surveys.

<sup>&</sup>lt;sup>66</sup> The 12 tribes are: Bay Mills Chippewa Indian Community, Grand Traverse Bay Band of Ottawa and Chippewa Indians, Hannahville Potawatomi Indian Community, Huron Potawatomi-Nottawaseppi Huron Band of Potawatomi, Keweenaw Bay Indian Community, Lac Vieux Desert Band of Lake Superior Chippewa Indians, Little River Band of Odawa Indians, Little Traverse Bay Band of Odawa Indians, Match-e-be-nash-she-wish Band of Potawatomi Indians of Michigan, Pokagon Band of Potawatomi Indians, Saginaw Chippewa Indian Tribe, and Sault Ste. Marie Tribe of Chippewa Indians, http://www.michigan.gov/fia/0,1607,7-124-5452\_7124\_7209-15452--,00.html accessed, March 19, 2003.

<sup>67</sup> http://www.itcmi.org/aihm.html, accessed March 19, 2003.

lives on Reservations in Michigan.<sup>68</sup> About 32 percent of the AI/AN population in Michigan is under the age of 18, compared to 20 percent of the overall Michigan population under age 18.<sup>69</sup>

As in many other States, poverty is prevalent throughout Michigan's AI/AN population. Twice as many AI/AN households in Michigan have incomes under \$10,000 as compared to households of all races.<sup>70</sup> Eighty-two percent of female heads of households on Reservations compared with 58 percent of off-Reservation heads of households live at or below the poverty level. This is due, in part, to the high level of unemployment among AI/AN members of Michigan's population, estimated at 54 percent in 1999 by the Bureau of Indian Affairs (BIA). Additionally, the BIA estimated that another 25 percent of Michigan AI/ANs were employed but living below Federal poverty guidelines, because the bulk of AI/AN employment is concentrated in low paying service jobs.<sup>72</sup> Education levels among AI/AN residents of Michigan are also lower, with 68 percent having a high school diploma or higher education in 1990 compared with 77 percent of the rest of the State's population.<sup>73</sup>

## AI/AN Health Services in Michigan

The Bemidji Area Office of the IHS, located in Bemidji, Minnesota, provides health care and funding to support health services for about 93,000 AI/ANs residing in five States, with Tribal facilities in Minnesota, Wisconsin, Michigan and Indiana, and urban centers in Minnesota. Wisconsin, Michigan, and Illinois. 74 Ojibwe (Chippewa) Indians are the most numerous of the 34 Tribes served by the Bemidji Area. Still occupying areas today where they earlier settled are the Ottawa, Potawatomi, Menominee, Ho-Chunk, and Sioux. Only the Oneida, a member of the Iroquois of upState New York and the Stockbridge-Munsee Mohican Band (originally from Massachusetts), were resettled in the area from greater distances.

The Bemidji Area office supports two IHS-operated short-stay hospitals, two health centers, and five health stations in three IHS Service Units. The Bemidji Area is unique, however, in that nearly all of the annual IHS funding allocation is distributed among the 34 Federally Recognized Tribes through contracts and self-governance compacts (97.4 percent as of FY 1998). Each Tribe contracts or compacts with IHS for health services ranging from outreach and contract health care to fully comprehensive health delivery systems, including environmental health services and sanitation facilities, and health facilities construction.

Under Public Law 93-638 contracts, Bemidji area Tribes run 24 health centers and 33 health stations. Health centers are open 40 or more hours per week with primary care providers on staff who also offer comprehensive ancillary services. Health stations are open less than 40

<sup>69</sup> http://mi.profiles.iaState.edu/census/census.aspx?Table=race&Fips=26000, accessed April 28, 2003.

<sup>&</sup>lt;sup>68</sup> U.S. Census Bureau, 2000 Census, Summary File 1.

<sup>&</sup>lt;sup>70</sup> The Great Lakes EpiCenter. Community Health Profile Minnesota, Wisconsin & Michigan Tribal Communities

http://www.msue.msu.edu/msue/imp/modii/ii493006.html, accessed 4/28/03.

<sup>&</sup>lt;sup>72</sup> The Great Lakes EpiCenter, 2001; http://www.msue.msu.edu/msue/imp/modii/ii493006.html, accessed April 28,

<sup>&</sup>lt;sup>73</sup> The Great Lakes EpiCenter, 2001.

<sup>&</sup>lt;sup>74</sup> The population is based on the official 2001 Headquarters User Population data of Federally Recognized Indians who use IHS services (http://www.ihs.gov/FacilitiesServices/AreaOffices/Bemidji/index.asp, accessed January 15, 2003.

hours per week, some with primary care providers and limited ancillary services.<sup>75</sup> The most common arrangement for AI/ANs living on a Reservation in Michigan is to have clinical services provided on the Reservation by the IHS or the Tribe, with contract services available in local communities for more complex care.<sup>76</sup>

The Bemidji Area's IHS budget is divided into direct service expenditures and Contract Health Service (CHS) dollars, used when care is not available on-site at IHS or Tribally operated facilities. Non-Indian community hospitals and referral centers are used, along with alternative resources that may be available, i.e., private health insurance, Medicare, Medicaid, and Veterans Affairs benefits.<sup>77</sup>

There are also other health and health insurance programs to address the health care needs of the AI/AN population in Michigan. Michigan's Family Independence Agency (FIA), which will be discussed in the next section of this report, administers many such programs.

### **Overview of Michigan State Government**

Based on information provided on its official State website, Michigan's public assistance, child, and family welfare agency (FIA) has collaborated with Michigan's Federally Recognized Tribes to develop a service delivery system that focuses on the pReservation of AI/AN families. The program, called Indian Outreach Services, strives to meet the needs of AI/ANs by serving as a liaison between State and Federal programs and Michigan's AI/AN communities. FIA has also established an advisory body known as the Implementation Team, which meets regularly to discuss child welfare issues such as foster care and adoption with respect to AI/ANs.<sup>78</sup> This partnership includes representatives from the FIA, Michigan's 12 Federally Recognized Tribes, the State's historic Tribes, AI/AN organizations, the Federal government, and other community and State organizations.<sup>79</sup>

Act 195, P.A. 1972 (Sections 16.711 - 16.720 of the *Michigan Compiled Laws*), established the Michigan Commission on Indian Affairs within the Executive Office of the Governor as an independent unit. The Commission's responsibility is to investigate problems common to AI/AN residents of Michigan and to assist Tribal governments, and AI/AN organizations and individuals with problems involving education, employment, civil rights, health, housing, treaty rights, and any other right or service due the AI/ANs of Michigan.<sup>80</sup>

### Michigan State Medicaid Program

The Michigan Department of Community Health (MDCH) oversees the Michigan Medicaid program. The Michigan program includes all of the services permitted under Federal law and regulations, as well as mental health and substance abuse services to persons with developmental disabilities; managed care services; and home and community-based care for

<sup>&</sup>lt;sup>75</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Bemidji/Bem.asp, accessed January 22, 2003.

<sup>&</sup>lt;sup>76</sup> http://www.senate.leg.State.mn.us/departments/scr/report/bands/RESTABLE.HTM, accessed January 22, 2003.

<sup>&</sup>lt;sup>77</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Bemidji/index.asp, accessed January 15, 2003.

<sup>&</sup>lt;sup>78</sup> http://www.michigan.gov, accessed March 12, 2003.

<sup>&</sup>lt;sup>79</sup> http://www.michigan.gov/fia/0,1607,7-124-5452 7124 7209-15443--,00.html, accessed April 25, 2003.

<sup>80</sup> http://www.michigan.gov, accessed March 12, 2003.

children, the aged, and the disabled.<sup>81</sup> The FIA conducts Medicaid eligibility determinations for MDCH through an inter-agency agreement.<sup>82</sup>

Michigan requires certain Medicaid beneficiaries to enroll in managed care organizations known as qualified health plans (QHPs). Sixty-six percent of Medicaid recipients are currently enrolled in QHPs.83 AI/ANs can be exempt from enrolling in QHPs by filling out and submitting by mail an exemption form to the MDCH. Other policies affecting the way Medicaid services are provided in Michigan include prior authorization, use of a prescription drug formulary, and an allowable imposition of a deductible of up to \$2.00 per family per month. Michigan also permits the imposition of co-payments for particular services ranging from \$0.50 to \$3.00.84

Other Medicaid programs that cover children and adults in Michigan include:

Group 2 Pregnant Women. A pregnant woman who has income that exceeds the income limit for Healthy Kids for Pregnant Women may be eligible for Medicaid under the Group 2 Pregnant Women program. If household income is over the income limit, persons may incur medical expenses that equal or exceed the excess income and still qualify for this program.

Maternity Outpatient Medical Services (MOMS). The MOMS program provides immediate outpatient prenatal coverage while a Medicaid application is pending. Other women who may be eligible for MOMS include teens who, because of confidentiality concerns, choose not to apply for Medicaid, and non-citizens who are eligible for emergency services only. The woman must use Medicaid benefits once she qualifies for the program under other guidelines. Prenatal health care services are covered by MOMS and/or Medicaid for the entire pregnancy and for two months after the pregnancy ends. An income test is imposed for all persons except teens.

Caretaker Relatives. Through the Caretaker Relatives program, Medicaid is available to eligible parents and people who act in the capacity of parents by caring for a dependent child who is not their biological or adopted child. There is only an income test for this program. If household income is over the income limit, persons may incur medical expenses that equal or exceed the excess income and still qualify for this program.

Two forms can be used to apply for Medicaid in Michigan: the FIA-1171 application, which can be used by any applicant; and the joint four-page Healthy Kids/MIChild application (the MIChild program is described in the next section) that can only be used by children and pregnant women. The FIA-1171 is a six-page, combined application for FIP, Medicaid, Food Stamps, State Emergency Relief and Child Day Care. 85

<sup>&</sup>lt;sup>81</sup> "Medicaid Health Care Services", Citizens Research Council of Michigan, CRC Memorandum No. 1072, March 2003

<sup>82</sup> Michigan Medicaid Eligibility Process Review Report, CMS Chicago Regional Office, October 2001.

<sup>&</sup>lt;sup>83</sup> Bernasek, C. et. Al. Case Study: Michigan's Medicaid Prescription Drug Benefit. *The Henry J. Kaiser Family Foundation: The Kaiser Commission on Medicaid and the Uninsured, January 2003.* 

<sup>&</sup>lt;sup>84</sup> "Medicaid Health Care Services," Citizens Research Council of Michigan, CRC Memorandum No. 1072, March 2003.

<sup>&</sup>lt;sup>85</sup> Michigan Medicaid Eligibility Process Review Report, CMS Chicago Regional Office, October 2001.

To apply for Medicaid or Healthy Kids, eligible persons must complete and submit an application by mail or visit their local FIA office, County public health department, or one of the MDCH authorized contract agencies (QHPs). The joint Healthy Kids/MIChild application is also available on-line on MDCH's website. Once an e-application has been submitted, the computer will determine the applicant's eligibility for the appropriate program. Eligible applicants receive a printed summary of the information provided for the application along with a signature page that must be signed and returned to the MIChild Office by mail or in person. Both Medicaid and Healthy Kids require annual redetermination.

The Michigan Assistance and Referral Service (MARS) is an on-line tool that allows Michigan residents to pre-screen themselves and identify programs offered by the State of Michigan that may help them with medical, nutritional, food, day care, temporary cash or other expenses. The screening tool provides the user with program information, and income estimator, application requirements, and where to find the appropriate office to apply for a program. FIA offices process applications for any program except the Women, Infants and Children (WIC) and MIChild programs; WIC offices handle Healthy Kids, Healthy Kids for Pregnant Women, MIChild, and WIC. In addition, the MDCH website allows applicants to apply on-line for MIChild, Healthy Kids, and Healthy Kids for Pregnant Women.

## **Michigan SCHIP Program**

MIChild is Michigan's State Children's Health Insurance Program (SCHIP), intended for low-income uninsured children of families with incomes higher than the limit for Healthy Kids. MIChild is a separate Title XXI program rather than a Medicaid expansion program. Like Healthy Kids, there is only an income test and coverage is provided for children who are under age 19. The child must be enrolled in a MIChild health and dental plan in order to receive services. While children can have other insurance coverage and still be eligible for the Healthy Kids program, most eligible for MIChild cannot have any other source of health insurance. AI/ANs, however, can have coverage through a Federal insurance program and still be eligible for MIChild.

MIChild, implemented in 1998, provides coverage to children under age 19 in families with incomes between 150 and 200 percent of the FPG. Michigan does not impose any copayments for the MIChild program but does charge a premium of \$5 a month for children in families with incomes between 151 and 200 percent of the Federal Poverty Level, regardless of the number of children in the family. Since 2001, however, AI/ANs have been exempt from paying premiums. Beginning in 2000, Michigan has allowed self-declaration of income for the re-enrollment process. The benefit package for MIChild is the same as the Medicaid benefits package that includes a variety of hospital and physician services, including vision, dental, and mental health services.

MIChild is administered by MDCH, which makes eligibility determination and contracts with multiple managed care providers to provide MIChild benefits. All enrollees are required to

be enrolled in a QHP. AI/ANs eligible for MIChild cannot "opt out" to be in a fee-for-service program. 86

#### **DESCRIPTION OF SITE VISIT**

### Overview

Prior to conducting the site visit, the team contacted Pam Iron (National Indian Women's Health Resource Center, Oklahoma), and Spero Manson (Division of American Indian and Alaska Native Programs, University of Colorado Health Sciences Center), Technical Expert Panel (TEP) members; David Baldridge (National Indian Council on Aging), and Ralph Forquera (Seattle Indian Health Board), Project Consultants; Jo Ann Kauffman & Associates), Project Consultant (who also sought suggestions from Glen Safford from the Great Lakes Inter-Tribal Council of Michigan and Kathleen Annette, Director, Bemidji Area IHS Office); Pam Carson and Ruth Hughes, CMS Native American liaisons in the Chicago CMS Regional Office (Region V); and Jenny Jenkins, Assistant to the Area Director for the Bemidji Area IHS Office. The team solicited advice on which communities the site visit team should visit in Michigan, who initial key contacts might be, and which issues specific to the State should be addressed in the study. According to the Case Study Design Report approved by CMS, the team solicited input on one Tribal area with Tribally managed health facilities, one Tribal area with direct IHS facilities, and one urban area with an Urban Indian Health Center that delivers medical services. The team also stressed that travel distances were an important consideration in recommending sites.

The goal of the three-day site visit was to meet with approximately 10 to 12 key organizations/people per State. Also, as noted in the Case Study Design Report, if the urban area recommended was located in the State capital, the team would also try to schedule in-person discussions with State Medicaid and SCHIP staff and IHS Area Office staff.

Representatives from the CMS Region V office said that all of the Federally Recognized Tribes in Michigan have either contracted or compacted with IHS. There is no IHS program in which direct health services are provided, but the IHS does fund programs administered by the Health Services Division of the Inter-Tribal Council of Michigan (ITC), which is based not far from Bay Mills in Sault Ste. Marie. Michigan is a difficult State to visit due to the great distances between Reservations. They recommended a combination of sites consisting of the Detroit Urban Clinic and two of the following Reservations: Bay Mills, Grand Traverse Band of Chippewa Indians, Little Traverse Band of Chippewa Indians, Saginaw Chippewa, and Sault Ste. Marie Tribe of Chippewa Indians.

In addition, CMS Region V staff noted that Grand Traverse Band has an established health program while the Little Traverse Band is less established, but developing a health program. In terms of enrollment outreach, Sault Ste. Marie and the Saginaw Chippewa have the most experience. Little Traverse Band has limited experience with outreach, as it is a newly Federally Recognized Tribe. Little Traverse is currently involved, however, in a joint IHS/CMS project to use Community Health Representatives (CHRs) to conduct outreach. For the project,

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<sup>86</sup> http://www.michigan.gov/mdch/, accessed March 12, 2003.

CMS provided training to the CHRs in early 2002 on eligibility for Medicare, Medicaid and SCHIP. There has been no evaluation of the program, so it is unknown how well the outreach project is being implemented or how successful it has been in raising awareness and program enrollment. The Tribe's involvement in the project, however, is an indication that it considers outreach important and visiting the Tribe could be helpful in that members would be able to communicate any difficulties they are experiencing in their outreach activities.

Finally, CMS staff recommended a site visit to the Detroit Urban Indian Clinic because it provides a great deal of direct care and conducts outreach. CMS staff said clinic does minimal third-party billing but does assist patients with accessing State services. CMS staff also said that the clinic has a good understanding of the results of their outreach on Medicaid and SCHIP enrollment.

Representatives from the Bemidji Area Office of the IHS suggested five Tribes for a site visit: Sault Ste. Marie, Little Traverse Bay Band, Saginaw Chippewa, Bay Mill, and Grand Traverse. The Area Office noted that because Bay Mills and Sault Ste. Marie are located close to each other (in fact, some staff members are contracted part-time by both Tribes' health facilities), it might be redundant to visit them both. They also noted that visiting one site on the Upper Peninsula and one in the Lower Peninsula would provide valuable diversity. The Area Office reiterated that all of Michigan's Tribes contract or compact with IHS to provide services to Tribal members so the site visit team would not be able to visit a fully IHS-run facility in the State.

The Area Office also added some information about the Detroit Urban Clinic. The clinic has four physicians who work on a part-time basis, providing direct medical services and alcohol and mental health programs. The clinic is primarily grant-focused, but generally considers third-party resources when making referrals. Area office staff said the clinic *does* engage in considerable third-party billing. Ralph Forquera of the Seattle Indian Health Board was also contacted regarding the urban program in Detroit, but he was not familiar with the program. He did mention that if the program only consists of referral services, the project team might benefit from selecting a third Tribe to visit rather than go to the Detroit clinic.

David Baldridge added that Sault St. Marie is very progressive and creative in terms of outreach and enrollment, and that they would be valuable to visit. Jo Ann Kauffman suggested the Saginaw Chippewa, Bay Mills, and Sault Ste. Marie as possible sites. She noted the importance of visiting Tribes that are experienced with third-party billing, as the site visit team should get a richer description and history of the obstacles and barriers with respect to third-party billing. Spero Manson suggested that the Little Traverse Band might not have enough history to obtain substantial information about their experience with third-party billing. As such, Grand Traverse Bay Band may be a better choice for the site visit. He also said that the Saginaw Chippewa Tribe is similar to Sault Ste. Marie in size and establishment but not as sophisticated with respect to outreach and billing. The goal for our site visit was to achieve a dichotomy in Tribal experience with Medicaid, SCHIP, and Medicare enrollment and billing by visiting a site on both the Upper Peninsula and the Lower Peninsula. In this respect, Spero Manson suggested that Sault Ste. Marie, Grand Traverse, and the Detroit urban clinic would be a good combination.

Based on the advice and information provided from the various sources, the team selected the Sault Ste. Marie Band of Chippewa Indians, the Grand Traverse Band of Ottawa and Chippewa Indians, and the American Indian Health and Family Services of South East Michigan (Detroit Urban Indian Clinic) for the site visits. This combination would enable to the team to visit Tribes with substantial experience in outreach and enrollment, visit Reservations on both the Upper and Lower Peninsulas, and visit an urban clinic that conducts outreach and assists patients with accessing State services. Initially the site visit team wanted to select one Tribe with gaming and one without in order to include examples of one Tribe with lower revenue and fewer resources, and one Tribe with higher revenue and more resources. However, because most Tribes in Michigan have a casino, the site visit team eliminated that criterion from the selection process.

After receiving CMS approval for the sites selected, the site visit team relied heavily on local Tribal and Urban Indian Health Center key contacts to determine which groups and individuals the team should speak with and at which places and times, in accordance with the Case Study Design Report. The team sent a list of people the site visit team would like to interview to an identified key contact at each site. The list included Tribal leaders, Tribal Health Directors and Tribal Health Board members, IHS Service Unit Directors, Contract Health Services Directors, Community Health Representatives/Community Health Aides, Title VI Directors/elder organization leaders, IHS hospital and clinic staff including alternative resource specialists, case managers, billing specialists, and patient benefits coordinators and counselors, urban Indian center and clinic staff, and other organizations that serve the AI/AN community (e.g., Area Agencies on Aging, out-stationed or County Medicaid/SCHIP eligibility workers, Indian Alcohol Treatment Centers, Indian Education Programs, and Tribal or County social services agencies).

Because the MDCH was not within feasible travel distance for the three-day site visit, the site visit team interviewed this organization by telephone following the site visit. The individuals and organizations with whom the site visit team met in Michigan or conducted follow-up telephone interviews are listed in Appendix IV.A.

### **Description of the Sault Ste. Marie Tribe of Chippewa Indians**

The Sault Ste. Marie Tribe of Chippewa Indians has about 31,000 enrolled members living throughout Michigan and the United States, and is the largest of all of the Federally Recognized U.S. Tribes in the Midwest/Great Lakes area. The Tribe, headquartered in Sault Ste. Marie, operates under a constitution and bylaws approved in November 1975 by the U.S. Secretary of the Interior, and is governed by an elected 12-member Board of Directors representing five geographic units in the eastern Upper Peninsula.

In 1984, the Board of Directors voted to open Kewadin Casinos. Kewadin's rapid success provided the funds to expand the Tribe's business holdings from one to five casinos and take ownership of 15 non-gaming businesses. In 1998, these businesses employed nearly 2,500 people, making the Tribe northern Michigan's largest employer. Revenues from the Tribe's casino and non-gaming businesses have been spent to purchase lands to increase Reservation holdings, finance the construction of new health centers, and pay for additional housing. It also

supports satellite offices in nine Michigan communities, extending membership services throughout the Tribe's seven-County service area of the eastern Upper Peninsula.<sup>87</sup>

Despite the success of these businesses in employing Tribal members, the overall economic picture of the Reservation is improving at a slow pace. For those not employed by the casinos, there is a high rate of unemployment, and wages are extremely low for Tribal members who do find employment outside of the casinos. The 1999 Bureau of Indian Affairs (BIA) National Labor Force Report indicates an overall unemployment rate of 71 percent for the Reservation with 22 percent of those employed living below the Federal Poverty Level.

The Sault Tribe is the largest Tribal health care provider in the Bemidji area. The Sault health program is Tribally operated under contract with the IHS. The Sault Tribal Health Division includes environmental, community and rural health programs, contract health services, elder care and meal programs, and traditional medicine. The Sault Tribe Health Division operates 10 health clinics in its seven-County service area, serving approximately 10,500 patients, 95 percent of whom are AI/AN. The main clinic, the Sault Ste. Marie Tribal Health Clinic, provides comprehensive outpatient services to Sault Tribe members, staff, and others. These services include medical, dental, pharmacy, laboratory, radiology, optical, audiology, physical therapy, community health services, contract health services, enrollment, eldercare services, environmental health, and Anishnabek Community and Family Services. Traditional medicine is also available at the clinics. Full time clinic providers include family practice, pediatrics, internal medicine, and family nurse practitioners. Specialty services are provided on a part-time basis and include podiatry, audiology, and minor surgery. The other nine clinics provide primarily general family practice services.

Contract Health Services (CHS) are available for Sault Tribe members residing in the Tribe's seven-County service area, providing services beyond those available through Tribal health facilities. Tribal members must have a referral from a Tribal provider to use CHS contracted providers. CHS funds are also used to provide financial assistance to Tribal members in the form of payment to the individual to cover co-pays, deductibles, spend downs, partial payments, and full payments for specialty services that the clinic cannot provide, for both public and private health insurance programs. Tribal members must apply for CHS yearly to be eligible to use CHS funds.<sup>89</sup>

#### Description of the Grand Traverse Band of Ottawa and Chippewa Indians

The Grand Traverse Band of Ottawa and Chippewa Indians was officially recognized as an Indian Tribe on May 27, 1980. The members are descendants of the various Ottawa and Chippewa villages who have inhabited northern Michigan for centuries. The Grand Traverse Band's Federal land base is approximately 1,100 acres with 3,500 members and 1,450 residing in its service area. The organizational structure of the Tribe's governmental services includes a governing body consisting of a Tribal chair and six other Tribal Council members, all of whom are elected by the Grand Traverse Band membership.

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<sup>87</sup> http://saulttribe.org/history.htm, accessed March 12, 2003.

<sup>88</sup> http://www.saulttribe.org/directory/page24.htm, accessed March 12, 2003.

<sup>&</sup>lt;sup>89</sup> http://www.saulttribe.org/health/healtha.htm, accessed March 12, 2003.

The Grand Traverse Band is among the largest employers in northern Michigan. The organization has been in the casino gaming business since 1984. In addition to Leelanau Sands Casino in Peshawbestown and Turtle Creek Casino in Williamsburg, the Band owns and operates two hotels, restaurants, a conference center and a convenience store. 90

The Grand Traverse Band operates one health clinic under contract with IHS, the Grand Traverse Band Family Health Clinic that serves its six-County service area. While non-Grand Traverse AI/ANs use the clinic (about 11 to 13 percent of its service population), the clinic's service population of 1,700 persons represents a 50 percent penetration of total Grand Traverse Band members. The clinic provides family practice, pediatric, and obstetrician/gynecology services. Because there is no IHS hospital nearby, the Clinic has a referral relationship with Munson Medical Center in Traverse City, which is approximately 20 miles from the Reservation. The clinic makes referrals to subspecialty providers at the hospital whose services are beyond the scope of those of the clinic. CHS funds are available for Tribal members residing in the six-County service area of Leelanau, Antrim, Benzie, Grand Traverse, Manistee and Charlevoix counties. 91

#### Description of The American Indian Health & Family Services of Southeast Michigan

The American Indian Health & Family Services of Southeast Michigan clinic is located in southeastern Detroit and serves primarily AI/ANs. The total user population of the clinic is approximately 3,300 individuals. Over one-half of the population the clinic serves is largely uninsured (56 percent) and, according to staff interviewed, are eligible for public benefits programs such as Medicaid. The only significant groups of uninsured clinic users *not* generally eligible for such programs are single adult female and male patients. According to those interviewed, virtually none of the clinic's patients have access to private health insurance; the primary potential sources of coverage for clinic users are Medicaid, and Medicare. Medicare enrollment is rare, however, because of the age composition of the clinic-user population. Most clinic patients are families and children (70 percent), with a smaller proportion of elderly (20 percent) and single adult men and women (10 percent).

The clinic receives no direct contract care funding from any of the Tribes its patients represent, although the Tribes do work with the clinic on several issues. The clinic is a Federally Qualified Health Center (FQHC) and as such receives some Federal grant money from the Health Resources and Services Administration's Bureau of Primary Health Care through Section 330 of the Public Health Service Act. As part of the FQHC requirements, the clinic is required to serve all the residents in their service area without regard to income or insurance status; provide services on a sliding fee scale basis (i.e., charges are assessed based on family income); be located in a designated medically underserved area or serve a medically underserved population; and, maximize all sources of patient and third-party payment in order to limit use of the 330 grant funds to cover any operating deficit. As such, the clinic pursues funding through a variety of sources including Federal, State, and private grants and contracts, third party reimbursements;

<sup>90</sup> http://news.corporate.findlaw.com/prnewswire/20030305/05mar2003075941.html, accessed March 12, 2003

<sup>91</sup> http://www.narf.org/nill/Codes/gtcode/travcode11health.htm, accessed March 12, 2003.

private donations; and patient fee collections. The clinic is an IHS Urban Program contractor and thus receives limited financial support from IHS.

FQHC's have requirements from the Federal government as to the types of services they must provide. Each FQHC is required to provide, either directly or through contracts or cooperative arrangements, basic primary health services. Primary health services include clinical care by physicians and nurses; diagnostic laboratory and radiology; perinatal services; preventive dental; immunizations; well-child exams; pediatric eye, ear and dental screening; family planning; and, pharmacy services as appropriate. They must also provide services that improve utilization and access such as case management; referrals for substance abuse and mental health services; outreach; transportation; translation services; and, patient education including nutrition counseling. In addition to these services, the clinic also offers traditional healing and acupuncture. For specialty services not offered at the clinic, patients are referred to local providers and hospitals. The Executive Director of the clinic is active in the ITC, and regularly raises issues pertaining to her clinic at these meetings. 92

## **Description of Other Organizations Interviewed** 93

Staff from the Health Services Division of the Inter-Tribal Council of Michigan, referenced earlier in the report, provide technical assistance, consultation and some direct preventive health care services to all Tribal communities, including urban communities, in the State of Michigan. The Health Services Division's preventive health care components consist of environmental health, health education, mental health, behavioral health, nursing, nutrition, and epidemiology. Staff also provide coordination for chronic and communicable disease prevention, with an emphasis on diabetes, cardiovascular disease, and HIV/AIDS. Maternal and child health programming, with an emphasis on high-risk families, is also provided.

In addition, the ITC provides technical assistance for Tribal health and human services systems development, maintenance, and expansion. The Health Services Office has been instrumental in developing quality assurance and health systems evaluation programming at the Tribal level. An additional component consists of Patient Registration and Health Insurance Portability and Accountability Act consultation services. The ITC also coordinates and serves as a liaison for training on public benefits eligibility and enrollment issues at the request of the Tribes. Finally, the Health Services Division of ITC functions as a health program resource developer, often seeking out State, Federal, university and other philanthropic organization resources that may be used by Tribes for health and human services systems development and service delivery.<sup>94</sup>

The Robert Wood Johnson Foundation (RWJF) has also been a facilitator for public benefits outreach in Michigan. Michigan was selected as a site for a pilot project under a \$47 million RWJF grant for Covering Kids, a nationwide initiative focused on enrolling the nation's

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<sup>92</sup> http://ohiopca.org/what is fqhc11.htm#Requirements, accessed May 1, 2003.

<sup>&</sup>lt;sup>93</sup> An interview with staff from the Great Lakes Inter-Tribal Epidemiological Center (EpiCenter) was also completed as part of the Michigan case study. While the EpiCenter does conduct public benefits outreach, this activity is conducted with Wisconsin tribes in conjunction with BadgerCare (Wisconsin's SCHIP program) and did not appear to pertain to this State report.

http://itcmi.org/healthservices.html, accessed March 12, 2003.

hard-to-reach, uninsured children in public benefits programs. This pilot project had a particular component targeted at AI/AN children in the Upper Peninsula (UP), which formed an advisory coalition for the project. The coalition included small hospitals, Tribal representatives, and health departments. To identify and enroll AI/AN children, the UP coalition collaborated with Tribal chairmen and the IHS to present information about public health insurance programs at powwows, naming ceremonies and other AI/AN activities; access informal networks for AI/ANs; and engage human resource directors of casinos to initiate communication with AI/ANs employees and customers.

#### FINDINGS: MICHIGAN MEDICAID AGENCY

#### Overview

Following the site visit to Michigan, the project team conducted a telephone interview with the Director of the Managed Care Support Division of the Michigan Department of Community Health (MDCH). In general, the Director said he believes the MDCH maintains a strong and collaborative relationship with the Tribes in Michigan. The State has a designated Tribal Liaison who attends Tribal health meetings, provides training on Medicaid and MIChild eligibility, and consults with Tribal leaders when program/policy changes are being implemented. The MDCH also has an established consultative process between the Tribes and the State. Tribes are given the opportunity to learn of upcoming policy and program changes and to provide feedback to the State regarding these changes.

The MDCH interviewee feels that there is less of an under-enrollment problem for AI/ANs in Michigan's Medicaid and MIChild programs than for the rest of the State's population. The Director believes the main reason for this is the successful outreach efforts of the Tribal health centers in Michigan, particularly the Sault Ste. Marie clinic, in identifying and educating potential eligible individuals and families and assisting Tribal members with completing applications.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

Although AI/AN under-enrollment in Medicaid and SCHIP was not perceived to be a large problem, the MDCH interviewee did report several barriers to initial enrollment in Medicaid and MIChild arising out of the application process.

As noted earlier in the report, two applications can be used for Medicaid in Michigan: the six-page FIA-1171 application, which can be used by any applicant; and the four-page joint Healthy Kids/MIChild application, which can only be used by children and pregnant women. Despite the availability of these applications on-line and at locations other than an FIA office, the application process presents barriers for some AI/ANs. First, many AI/ANs are not aware of alternate methods of applying for the programs other than physically going to a local FIA office. This lack of awareness presents several problems (e.g., transportation and issues of privacy and pride). The fact that some AI/ANs believe they have to go into an FIA office intensifies this

reluctance. This stigma also presents a barrier for some AI/ANs who may be eligible for the Medicare Savings Programs but are reluctant to enroll.

Second, even for AI/ANs who know it is not necessary to go into an FIA office and are aware of how to access the application on-line or at a non-FIA location, not all are able to fill out their applications without assistance.

Finally, the MDCH interviewee said that some AI/ANs, whether or not they know that they can apply for a program without physically going to an FIA, are hesitant to enroll because they know they cannot secure reliable transportation to actually use Medicaid services. That is, even if they are enrolled, they do not have access to reliable transportation methods that would allow them to regularly visit their assigned primary care physician's office.

#### Barriers to Maintaining Enrollment

The transportation barrier is particularly exacerbated when AI/ANs who are not aware that Michigan exempted AI/ANs from being required to enroll in a managed care program think that they must specify that they want to enroll in managed care. They are then assigned to a managed care provider. However, these members then may not want to go to their assigned provider or that provider may be geographically inaccessible to them given the extent of their access to transportation. The result is that they continue to access the Tribal facility as a managed care enrollee. As a result, the facility is not able to bill for services provided.

Finally, the MDCH director also said that, because some Tribal members (two out of the twelve Tribes in Michigan make per capita payments to Tribal members) receive dividend payments from gaming revenues on a monthly basis, fluctuating income causes these AI/AN recipients to cycle on and off Medicaid.

#### <u>Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings</u> Programs<sup>95</sup>

The MDCH Director did not document any barriers to Medicare or the Medicare Savings Programs.

#### Strategies to Increase Enrollment in Medicaid and SCHIP

The MDCH Director suggested several strategies to increase AI/AN enrollment in Medicaid:

• **Tribal Liaison.** MDCH's Tribal Liaison regularly attends Tribal health meetings to stay aware of current issues and to provide updates to the Tribes on policy changes. For

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<sup>&</sup>lt;sup>95</sup> The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

example, upon request from Tribes, Michigan exempted AI/ANs from the mandatory enrollment in a managed-care organization (with the exception of MIChild enrollees). AI/ANs in Michigan have also been exempted from having to pay MIChild premiums.

- **Regular Training.** The Tribal Liaison also provides regular training on Medicaid eligibility throughout the State. In addition to the regularly scheduled training, the Tribal Liaison provides additional training to Tribes on request. This training is provided to Tribal staff who regularly assist Tribal members in completing applications.
- **Knowledgeable Tribal Staff.** The MDCH director felt having Tribal staff members who are knowledgeable about eligibility issues, the enrollment process, and are able to help Tribal members complete applications is key to increasing and maintaining enrollment in Medicaid/MIChild. He stated that the presence of trained Tribal members who can identity and assist AI/AN potentially eligible persons through the enrollment process is more effective then having FIA workers out-stationed on Reservations. He believes that Tribal members will always be more accepted and trusted than "outsiders" and can, therefore, more effectively encourage Tribal members to enroll in these programs.

#### FINDINGS: SAULT STE. MARIE TRIBE

#### Overview

During our site visit to Sault Ste. Marie, the site visit team discussed program enrollment barriers and solicited strategies to increase enrollment in Medicaid, MIChild/Healthy Kids, and Medicare with the Tribal Health Director, the Contract Health Services Director, the Elder Meal Program Director, the Community Health Director, the Business Office Manager, medical staff, Patient Benefits Coordinators, the Health Board Chairman, and the Agency for Children and Family Services Director of the Sault Ste. Marie Health Center. In addition, two representatives from the Health Services Division of the Inter-Tribal Council of Michigan (ITC) were present at the meeting. As such, findings from conversations with the ITC staff have been folded into the findings from discussions with Sault Ste. Marie health staff. Following the site visit, the site visit team also conducted telephone interviews with the Eldercare and the Elder Meal Program Directors.

In general, staff of the Sault Ste. Marie Health Center did not perceive under-enrollment in Medicare, Medicaid, or MIChild to be a large problem for the Sault Ste. Marie Tribe. The Sault Ste. Marie Department of Health and Human Services, the largest Tribal health care provider in the Bemidji area, is well organized and benefits from revenues earned from the Tribe's casino and non-gaming businesses.

Tribal health staff interviewed did not know the actual number of Tribal members eligible but not enrolled in Medicare, Medicaid, and MIChild. However, they estimated that most who are eligible for Medicare Part A are enrolled and that only a small portion of those who are eligible for Medicare Part B, Medicaid, and MIChild are not enrolled in those programs.

While under-enrollment may not be a large problem, some Tribal members still face barriers to enrolling in health programs. The primary barriers, as reported by health staff, are lack

of outreach, resulting in a lack of knowledge and understanding of the programs and their benefits; lack of reliable transportation; and, a general feeling that members do not need to enroll in these programs because they have access to Tribal facilities that provide comprehensive health and medical services.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Under-enrollment in Medicaid for the Sault Ste. Marie Tribe, although estimated to be low, is more of a problem than under-enrollment in Medicare according to those interviewed. Interviewees said that the main reason for under-enrollment in Medicaid is lack of awareness, followed, or exacerbated by, lack of outreach to this population. The second primary reason is that some eligible Tribal members feel that they do not need to enroll in the Medicaid and MIChild programs because the Tribal clinic offers comprehensive services.

#### Barriers to Initial Enrollment

Interviewees most frequently reported the following barriers to initial enrollment in Medicaid and MIChild:

- Many Tribal members are not aware that these programs exist. Health staff interviewed believes the main reason for this lack of awareness is limited outreach targeting Tribal members
- Staff also believe that some Tribal members may actually be aware of the programs but do not understand their benefits, and some are not motivated to go through the effort of enrolling when clinic and Contract Health Services are available and comprehensive.
- Securing transportation to the County FIA office presents a challenge for many members. Some AI/ANs are not aware that there are alternate methods to applying for the programs other than in person at a local FIA office. This lack of awareness presents several problems. Along with the difficulties for many AI/ANs in securing reliable transportation to an FIA office, some AI/ANs are reluctant to visit an FIA office due to issues of privacy and pride and a hesitancy to disclose personal information to strangers.
- The need for application assistance is also a barrier to enrollment. For those AI/ANs who know it is not necessary to go into an FIA office and are aware of how to access the application on-line or at a non-FIA location, not all are able to complete an application without assistance. Because the applications bears the FIA name or because they do not know where else to seek help, many AI/ANs feel that they need to go into an FIA office to obtain help in filling out the application. As such, they face the same enrollment barriers as do AI/ANs who believe the only way to apply for a program is to physically visit an FIA office.
- Lack of transportation to visit providers' offices presents another barrier to enrollment. Some AI/ANs, whether or not they know that they can apply for a program without physically going to an FIA, are hesitant to enroll because they know that they do not have the ability to secure reliable transportation to actually utilize the program. The transportation barrier is particularly exacerbated when AI/ANs who are not aware that

they can opt out of Medicaid/MIChild managed care fail to specify that they want to opt out of managed care at the time of enrollment and are automatically assigned to a managed care provider. Members may not want to go to that provider or that provider may be geographically inaccessible to them given the extent of their access to transportation.

- There is a stigma associated with enrollment in Medicaid and MIChild. According to the interviewed health staff, many Tribal members associate Medicaid and MIChild with welfare and, thus, are often reluctant or too proud to enroll in these programs. This barrier is compounded by some Tribal members' perceptions of negative experiences at County FIA offices involving an attitude of presumed ineligibility from FIA eligibility workers.
- Many Tribal members feel the enrollment requirements are confusing and the enrollment process is difficult, particularly due to the relatively high level of illiteracy among the Tribe's population. Some also feel the requirements are too burdensome. One example given was that if a person was denied enrollment, regardless of the reason for denial, the person would likely not attempt to re-apply.

#### Barriers to Maintaining Enrollment

- Interviewees most frequently reported the following barriers to continuing enrollment in Medicaid and MIChild:
- Interviewees noted that redetermination for Medicaid is required every six months (although Medicaid staff indicated that redetermination is only required once a year), requiring eligible persons to have to complete the application process so frequently that they generally will not do so unless they are experiencing acute care needs. Consequently, by the time the member gets through the redetermination process, they have already received the services for an acute medical situation. These services cannot be billed to Medicaid, since the individual was not on Medicaid at the time of the service.
- Due to seasonal and lack of steady, full-time employment, some Tribal members' incomes fluctuate, often on a monthly basis. Thus, an individual can be eligible for Medicaid and/or MIChild one month and be ineligible the next month, resulting in the need to re-apply or re-certify more than once a year.

### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

According to those interviewed, under-enrollment in Medicare Part A is a small problem for the Tribe. There are several Tribal members who are not enrolled in Part B, however, because they feel they cannot afford to pay the premiums. Many members are also unaware of the penalty applied by Medicare for not enrolling in Part B at the time of initial eligibility. Of those who feel they cannot afford the Part B premium, most probably do not meet the income requirements for Medicare Savings Programs eligibility according to the health staff. Of those eligible for the Medicare Savings Programs, they are generally either unaware of the programs or are "too proud" to enroll because of the social stigma associated with welfare. Also, at the time of the site

interviews, many staff members indicated they were not aware of the Medicare Savings Programs and, therefore, not able to educate those who may be eligible.

The interviewees reported the following reasons for under-enrollment in Medicare and the Medicare Savings Programs:

- Many elders are not aware that they may be eligible for the Medicare Savings Programs.
   Staff mentioned that there is a lack of outreach targeting elders about the programs. Also, some clinic staff themselves indicated they are not familiar with the Medicare Savings Programs and, therefore, are not able to educate or inform members of the programs and benefits of enrolling.
- Staff noted that the welfare stigma associated with Medicaid coverage discourages some elders from enrolling in the Medicare Savings Programs.
- One of the primary barriers for elders not enrolled in Medicare Part B is that they feel they cannot afford to pay the Medicare Part B premium. In addition, of those who are not enrolled in Part B, many are not aware of penalties for enrolling in Part B after their initial eligibility period. When they realize they need to enroll on Part B, they are not able to afford the penalty, which accrues yearly.
- While there are elderly AI/ANs who are aware of the programs, many still choose not to enroll for a variety of reasons. The Federal Trust Responsibility is particularly important with respect to understanding why some elder AI/ANs do not want to enroll. While much of the younger population has accepted the idea of public health insurance programs, many elders feel very strongly that the Federal government promised them health care and that they should not have to enroll in programs intended for the non-AI/AN population or for individuals who fall within certain income guidelines to receive that care. In addition, many elder AI/ANs also have a general feeling of mistrust towards the government because of the historical tension between AI/AN governments and the U.S. government.

#### Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

The Sault Ste. Marie Tribe is currently working with the MDCH to develop a process that will allow the Tribe to determine eligibility and enroll members in Medicaid directly. Many interviewed feel this would greatly increase enrollment for the small group who are eligible but not enrolled in Medicaid. When the Tribe began directly administering the WIC program, enrollment in this program increased substantially. Interviewed staff members had additional suggestions for increasing enrollment in the three programs:

• Comprehensive Process for Identifying Eligible Tribal Members. The Tribe would like to develop a comprehensive process for identifying members who are eligible for these programs and assisting them through the enrollment process. This process would include a "tickler" system to identify Tribal members due soon for program redetermination. To develop such a comprehensive process, the Tribe would like assistance from the State in receiving regular and updated training for staff on program

eligibility and enrollment issues. Although the State currently provides some training, staff overwhelmingly felt more training was needed.

- Additional Patient Benefits Coordinators. The Tribe would also like to receive
  additional IHS or other source of funding to hire more Patient Benefits Coordinators or
  other similar positions so it can provide more outreach and one-on-one assistance to
  Tribal members, something they feel is key to increasing program enrollment. Currently,
  the Tribe is undertaking efforts to develop alternative resources to hire more outreach
  staff.
- Additional Transportation Options. Because transportation was considered by the Tribe to be a major barrier to enrollment, they would like assistance in providing transportation options to their members. The Tribe currently funds a medical transportation program for members 60 years and older. However, for those Tribal members not eligible for this transportation program, many feel that even if they are enrolled in a program, lack of transportation makes it difficult for them to access the services available to them under the program. For this reason, they may be reluctant to even go through the enrollment process at all, even if they know they are likely eligible for a program. One example given was additional funds to either purchase or contract for handicapped-accessible vans or drivers to provide transportation services for Tribal members
- Indian Outreach Worker at County Medicaid Offices. Some County FIA offices have a designated Indian Outreach Worker, but not all do. For those that do have designated outreach workers, they usually have high caseloads and little time to commit to outreach activities. The health staff suggested that if the State could increase the number of Indian Outreach Workers, particularly those who serve as liaisons with the Tribes, they would be able to reach more program-eligible members.

#### Other Issues

ITC staff raised an additional issue during the meeting: the fact that there are people in the Tribal community who are not officially enrolled Tribal members, such as Indian and non-Indian spouses and non-eligible descendants. Although not enrolled members, these people still look to the Tribe for their health care. These individuals are often the most in need of coverage.

#### FINDINGS: GRAND TRAVERSE BAND OF OTTAWA AND CHIPPEWA

#### <u>Overview</u>

The Grand Traverse Band operates one health clinic under contract with IHS, which serves its six-County service area's population of 1,700 persons. The site visit team discussed program enrollment barriers and solicited strategies to increase enrollment in Medicaid, MIChild/Healthy Kids, and Medicare with the Reservation's Clinic Administrator, several Community Health Representatives, a Patient Benefit Coordinator, representatives from Contract Health Services, and a representative from the Tribe's Accounting Office.

Overall, third party reimbursement at Grand Traverse's clinic has increased since the Tribe was Federally Recognized 17 years ago, according to clinic staff interviewed. Before that time, the health clinic operated primarily on CHS funds. According to those interviewed, currently the clinic's total budget is made up of IHS base funding, third-party billing, and Tribal contributions (5 to 10 percent). At the time of the interview, staff were unaware how much of the clinic budget came from third-party billing. They estimated that 60 percent of the funds for CHS services comes from the Tribe, while 40 percent comes from Federal IHS base funding. Currently, Blue Cross Blue Shield (BCBS) administers the Tribe's CHS program so members are able to access services anywhere. When possible, the Tribe bills for Medicare, Medicaid, and MIChild, with the Tribe being the payer of last resort.

Overall, the consensus of those interviewed was that enrollment in Medicaid, MIChild, and Medicare is a moderate problem on the Grand Traverse Reservation. In general, there is more of a problem with under-enrollment in Medicaid and MIChild than in Medicare. Current efforts to enroll members in these programs have primarily focused on reaching and educating people who visit health facilities. Tribal members who do not access medical services tend to be the largest group of under-enrolled.

Clinic staff noted that the current one-page redetermination form for MIChild has been helpful in increasing Tribal enrollment. Previously, the form was over 20 pages, extremely complicated, and served as the same form for many diverse public benefit programs. Additionally, the new form assumes presumptive eligibility for MIChild and Healthy Kids, and at some local FIA sites, is available on-line. In these cases, applicants can receive a presumptive eligibility determination within a minute of electronically submitting a completed application. While this is helpful, AI/ANs mistrust of FIA workers is still often an issue. Most AI/ANs feel more comfortable talking to another Tribal member at a Tribal health facility, where they can later mail in the application if they feel comfortable applying.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

Interviewees most frequently reported the following barriers to initial enrollment in Medicaid and MIChild:

- A persistent welfare stigma associated with Medicaid and MIChild. AI/ANs continue to view them as welfare programs because of Medicaid's past association with cash assistance programs.
- FIA workers have told some Band members that they are ineligible for Medicaid or MIChild prior to the start of the application process. This attitude reportedly dissuades many from going to County offices to apply for programs or to seek help in filling out applications. (While it is not necessary to go to an FIA office to apply for these programs, interviewees said that some AI/ANs are not aware of alternate methods (e.g., by mail, online, or seeking help from a patient benefit coordinator at a Tribal or IHS health facility)).

- Clinic staff feel that a lack of information about their service population is a barrier to increasing enrollment. They do not have a grasp on how many eligible persons are not enrolled due to the fact that they only encounter individuals if they come into the clinic. Because there is little outreach outside of the clinic, staff does not know how many members may be eligible but are not coming into the clinic.
- Many AI/ANs do not understand that they can opt out of Medicaid/MIChild managed care. Because of this lack of awareness, members often do not specify that they want to opt out of managed care at the time of enrollment and are automatically assigned to a managed care provider. However, members often do not want to go to that provider and continue accessing the Tribal facility as a managed care enrollee. As a result, the facility is not able to bill for services provided and has less of an incentive to encourage patients to enroll in Medicaid.
- Lack of transportation was identified by staff as a major barrier to enrollment in Medicaid, SCHIP, and Medicare. In fact, the clinic conducted its own survey on enrollment barriers. Some AI/ANs are hesitant to enroll in programs because they know that they do not have the ability to secure reliable transportation to access program services. The transportation barrier is particularly exacerbated when AI/ANs who are not aware that they can opt out of Medicaid/MIChild managed care fail to specify that they want to opt out of managed care at the time of enrollment and are automatically assigned to a managed care provider. Members may not want to go to that provider or that provider may be geographically inaccessible to them given the extent of their access to transportation.

#### Barriers to Maintaining Enrollment

Interviewees discussed the following specific barriers to maintaining enrollment in Medicaid and MIChild:

- Interviewees said that the redetermination process itself causes many Medicaid and MIChild AI/AN recipients to be dropped from the programs.
- While the FIA sends the clinic a list of patients due for redetermination, as well as a notice to the individual, these systems are "hit or miss." Tribal members will sometimes call or come in to see Patient Benefit Coordinators at the clinic if they need assistance with the redetermination paperwork, but this is based on their own initiative. More often than not, the member will allow enrollment to lapse rather than deal with the paperwork if they do not have a health situation that requires immediate medical care.
- In addition, the fact that Medicaid enrollees are faced with disenrolling and re-enrolling on a monthly basis if their income changes creates periodic spells of uninsurance. MIChild, on the other hand, uses a 12-month continuous eligibility period, which means that enrollees may stay enrolled in the program regardless of changes in income for a 12-month period.

### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Because clinic staff only encounters Tribal members who come into the clinic for services, they do not have a good idea of how many Tribal members may be eligible but not enrolled in the Medicare Savings Programs. Clinic staff interviewed said they believe that the primary barrier to enrollment in the Medicare Savings Programs is a lack of awareness of their existence. In fact, at the time of the interview, several clinic staff indicated they were not aware that the State's Medicaid program would help pay Medicare Part A and B costs for Tribal members who are dually eligible for both programs.

Interviewees discussed the following barriers to maintaining enrollment in Medicare:

- Clinic staff stated that most members eligible for Medicare who visit the clinic are already enrolled in Part A. There is, however, a moderate level of under-enrollment in Part B, primarily because Tribal members feel they cannot afford the Part B premium. Staff, particularly Patient Benefit Coordinators, indicated they have developed and maintained a good relationship with the local Social Security office. As a result, they feel they are able to coordinate well with Social Security to address the issue of underenrollment in Part B. In addition, the Tribe has considered reimbursing all Tribal members for Part B premiums because they believe it might be less expensive in the long run for members were they able to receive preventive care services provided under Part B.
- Another issue with respect to Medicare and the Medicare Savings Programs is that many Tribal elders feel that AI/ANs should not have to apply to the State for health programs because of "the Federal Trust Responsibility." This attitude is much more prevalent among elder AI/ANs, who are both more traditional and more cognizant of some of the historical tensions betweens AI/ANs and the U.S. government. As such, one of the significant enrollment barriers for elder AI/ANs who are aware of Medicare and the Medicare Savings Programs is the belief that, because the Federal government is obligated by treaty and law to pay for health care for AI/ANs, they should not have to enroll in programs designed for the non-AI/AN population or be required to pay out-of-pocket for any type of medical care.

#### Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

The interviewees discussed the following strategies, currently in place, for increasing Tribal member enrollment in the three public programs:

- Screening Process. A screening process that begins at patient registration, which interviewees perceive to be the most effective method the clinic employs. Patients who list no alternative resource for paying for medical care upon screening by a registration clerk are directed to one of the clinic's Patient Benefits Coordinators for additional screening and application assistance for Medicaid, MIChild, and/or Medicare.
- Clinic staff assistance with application enrollment at health fairs. Health fairs, organized by clinic staff, provide a "one-stop shop" in the community where members

can receive outpatient services and information on applying for public benefits programs. This was originally a one-day, one-time event, but because it was effective, staff have conducted several and would like to make them regular events.

- The "Caregiver Program" a clinic-sponsored program for Tribal elders. This program assists elders with a variety of financial, daily life, and health issues. Elders having problems accessing medical care or Social Security are referred to the clinic, where they are able to meet with a Patient Benefits Coordinator. The interviewees said that elders are often a very difficult population to reach, and require a great deal of outreach, home visits, and one-on-one interaction. Through this program, Caregiver staff is able to develop a relationship of trust. As a result, elders are more likely to be willing to talk with Benefits Coordinators and other clinic staff about public benefits programs.
- Community Health Representative support. CHRs play a particularly important role in increasing Tribal members' awareness of public benefits programs because they regularly go into members' homes. Currently, the Tribe employs four CHRs. Increasingly, CHRs are becoming aware of the issue of public benefits and will notify the clinic when they think someone is eligible, allowing clinic staff to follow up.

Despite the Tribe's current enrollment strategies, interviewees felt there is a need for additional activities to ensure that all eligible Tribal members are enrolled in public insurance programs. These include:

- Additional State/IHS resources to hire supplemental clinic staff for enrollment assistance activities. Interviewees said this is particularly important because the clinic's service area is composed of six far-reaching counties. Also, because many Tribal members distrust the government, particularly those who have had negative experiences with FIA case caseworkers, they are reluctant to go to the FIA office to enroll. Therefore, staff spends a lot of time explaining to members the benefits of enrolling and how third-party reimbursement will benefit the Tribal member and the Tribe as a whole. Because this one-on-one assistance requires substantial staff time, additional resources to hire more staff would allow for more effective education and outreach.
- Interviewees identified the need for additional State-based training. This should include updates and follow-on training regarding program enrollment processes and eligibility verification for Medicaid and MIChild. While FIA conducted initial training on the MIChild program when it was first established, no subsequent training has been initiated by the State. The State has been willing to provide training to Patient Benefits Coordinators at the clinic's initiative, providing that the clinic coordinates the logistics of the training. Staff mentioned that it would be helpful to have more of this training at regular intervals.
- Raise Awareness of Programs. Clinic staff said they could include information on eligibility and enrollment issues in their Tribal newsletter to raise awareness about the importance of enrolling in Medicaid, MIChild, and Medicare, and how the Tribe as a whole would benefit.

#### Other Issues

Interviewees suggested that health clinic staff should receive compensation for the FIA services they provide. Staff expressed resentment that they are doing the job of the FIA but are not being compensated by the State. Essentially, the Tribe's health dollars are being used to do the job that FIA should be doing. Although Tribal health staff believes they are more successful at enrolling AI/ANs than FIA staff at an FIA office, the Tribe is losing out because the State should be reimbursing them for doing the State's job. However, payment by the State cannot be rendered to the clinic for application assistance.

# FINDINGS: AMERICAN INDIAN AND FAMILY SERVICES OF SOUTH EAST MICHIGAN

#### Overview

The site visit team interviewed the Executive Director of the American Indian and Family Services of South East Michigan health clinic. The Executive Director indicated significant under-enrollment existed in the public insurance programs among urban area AI/ANs, particularly in Medicaid. The primary reason reported is AI/AN discrimination at FIA offices. She estimated there is not as much under-enrollment in Medicare because of other outreach programs that address enrollment in Medicare (e.g., programs sponsored by the Saginaw Chippewa). However, many of the clinic's AI/AN patients are not eligible for Part A because of the 40 quarters work rule. Currently, she believes there is very limited use of the Medicare Savings Programs because outreach to this population is such a challenge.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

The Executive Director reported the following specific barriers to initial enrollment in Medicaid and MIChild:

- Many AI/ANs feel they have been discriminated against at FIA offices. The Executive Director said this was a major barrier and the main reason for AI/ANs not wanting to enroll in Medicaid or MIChild. Despite the availability of the applications on-line and at locations other than an FIA office, many AI/ANs are not aware of alternate application methods other than in person at an FIA office.
- Even for AI/ANs who know that it is not necessary to go into an FIA office and are aware of how to access the application on-line or at a non-FIA location, many require in-person assistance in completing the form. Because the applications bear the FIA name, they do not know where else to seek help. Or, because AI/ANs traditionally prefer (or "have been conditioned by the I/T/U system into preferring") one-on-one and face-to-face assistance, many feel they need to go into an FIA office for application assistance.
- The State does not provide general staff training specific to AI/ANs because of their low numbers in the State. The clinic's staff feels this population is ignored and that AI/ANs

are not of interest to the State. This lack of training, coupled with the fact that the clinic is very resource constrained, prevents staff from being able to provide adequate education and assistance to patients who may be eligible for these programs.

- AI/ANs who are "working poor" generally believe that it is typical for them not to have health insurance. Because of the low expectations of this population, clinic staff is challenged with motivating these individuals to seek health care, as well as with providing enrollment assistance.
- Another barrier is the reluctance on the part of, and lack of help for, AI/ANs who are denied benefits for which they have applied. Many AI/ANs do not realize that a denial can be appealed and overthrown. In fact, sometimes a denial from one program is necessary to pursue enrollment in another. Denials are especially difficult for clinic staff to address, because many AI/ANs do not question denial letters. For those who wish to appeal denials, the clinic does not have the capacity to provide legal assistance. For those who choose to challenge a denial, the closest legal aid clinic specializing in AI/AN issues is the Michigan Indian Legal Fund Association in Traverse City.
- Lack of awareness and understanding of program benefits is another enrollment barrier cited by the Executive Director. Clinic staff finds that AI/ANs, in general, are not aware of the public benefits programs for which they are eligible. Those that do know about the programs are hesitant and fearful to apply for a variety of reasons including discrimination, fear of eState recovery, etc. Walking an AI/AN client through the enrollment process can be successful, but requires a lot of time and one-on-one assistance, which clinic staff often do not have the time to provide.

#### Barriers to Maintaining Enrollment

The Executive Director reported the following barriers to maintaining enrollment in Medicaid and MIChild:

- The State's six-month redetermination process causes many patients to be dropped from Medicaid. (According to the Medicaid office, however, the redetermination process takes place once a year.) Some patients bring redetermination forms to the clinic for help and successfully re-certify. Others, however, get disenrolled because they ignore the mailing from the Medicaid office; are not experiencing an acute medical need at the time the redetermination forms arrive; misplace the forms; fail to seek assistance with the forms, or are unable to find appropriate assistance. Each time a disenrollment occurs, clinic staff must start the process from the beginning to help these people get back on the programs. This is a labor-intensive process which is inefficient for the staff, clinic, and patients.
- Women are often disenrolled from Medicaid after they give birth because they are no longer eligible based on pregnancy criteria. While many of these women could stay on Medicaid through other eligibility criteria, they often do not pursue this in time to stay on the program without a period of disenrollment. The clinic used to have an OB/GYN program through which clinic staff assisted re-enrollment efforts, but had to stop providing prenatal care due to the financial risk.

#### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

The Executive Director believes there is not as much under-enrollment in Part A Medicare as there is in Medicaid because of other outreach programs address enrollment in Medicare (e.g., programs sponsored by the Saginaw Chippewa). However, some patients are not eligible for Part A because of the 40 quarters work rule. In this case, clinic staff pursues SSI and Medicare Part B coverage for the patient through the Medicare Savings Programs. Part B Medicare enrollment remains a problem because many AI/ANs feel they cannot afford the Part B premium. The Executive Director discussed the following factors as limiting AI/AN use of the Medicare Savings Programs:

- Outreach to this population is a very large challenge. While AI/ANs generally experience the same problems as other dual eligible populations in that some are not aware of the programs, some do not know where to go for more information, and some need additional one-on-one assistance to help them through the enrollment process, AI/AN dual-eligible populations have unique communication needs. For example, they may be wary of government programs due to the historical tension between the U.S. government and AI/AN Tribes. They may also fear loss of what they already have, invasion of privacy, or discrimination. Also, Tribal oral traditions, lack of education, and English as a second language, may mean that print materials that work for the non-AI/AN population are ineffective for many AI/ANs, particularly the elderly.
- Also, AI/AN elders in general are especially distrustful of "mainstream systems and programs." Whether they are members of tightly knit AI/AN families or live alone, elders often remain separated from the mainstream by an array of linguistic, educational, and cultural barriers. Some particularly relevant obstacles include the fact that AI/AN traditional ways of life are learned through experience. Word of mouth travels quickly and many positive experiences may be necessary to overcome just one negative experience, such as perceived discrimination at County FIA offices. Also, elder AI/ANs may lack an understanding of health care provision outside of the IHS/Tribal/Urban health care system.
- Urban AI/ANs are often very difficult to locate, and, if located, traditional AI/AN elders tend to be reserved and may not readily talk about health issues until they experience a medical crisis. Successful outreach is time-consuming, and thus costly, because the elder must develop trust and confidence before he/she will share sensitive information.
- The Executive Director also stated that AI/ANs are resistant to going through the enrollment process on their own. She felt the main reasons for this reluctance are fear of discrimination and lack of awareness and understanding of the programs. As a result, unless clinic staff provides individual assistance though the enrollment process, many of their patients will not enroll. Currently, the clinic does not have enough staff or resources to provide this one-on-one assistance.
- The urban clinic staff feels that there is very little support from the State to enroll individuals (all, not just AI/ANs) in the Medicare Savings Programs. Their perception is that the State offers the programs because it is a requirement to receive Medicaid

matching funds from the Federal government, but purposely fails to market the programs to their intended recipients in an effort to save money.

### Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

The American Indian and Family Services of South East Michigan clinic's primary activity to increase program enrollment consists of patient screening and enrollment assistance. If someone comes to the clinic who is not enrolled in any program, an outreach worker screens the person, first evaluating the likelihood of eligibility. Outreach workers then provide assistance with completing forms and even accompany applicants to the appropriate FIA office if needed. Clinic staff felt that while this method is time consuming, it is more effective than simply distributing information about programs and leaving individuals to follow through with the application process themselves. While staff encourages patients to enroll in programs for which they are eligible, they also stress that it is ultimately the patients' decision to enroll in all the programs for which they are eligible or no programs at all.

Because the clinic is unable to screen and assist all patients that may be eligible for programs, the Executive Director suggested that additional funds for the clinic to hire additional program-trained clinic staff and provide additional program training for existing clinic staff would increase program enrollment. Clinic staff overwhelmingly feel they need additional, trained staff to provide the needed outreach and assistance to their patients. Staff noted that there is very little outreach for the non-clinic user AI/AN population in Detroit, so it is particularly important to increase outreach efforts to target AI/ANs in the community who do not already come into the clinic. They believe the key to reaching eligible AI/ANs, as well as convincing them and assisting them to enroll, is having well qualified outreach workers to provide the necessary one-on-one interaction. Clinic staff stressed it would be particularly useful to train more AI/AN staff, who would likely be more trusted by AI/AN individuals.

The Executive Director discussed the following strategies that the urban clinic uses to increase AI/AN enrollment in the Medicaid, MIChild (SCHIP), and Medicare:

- Outreach in the community and in-reach in the clinic. Currently, clinic staff regularly conducts outreach in the clinic itself (i.e. by identifying program and referral needs for patients who come into the clinic) as well as conducting outreach in homes and communities in Detroit. Both of these types of outreach have been very successful, particularly because clinic staff takes care to reach out to AI/ANs in culturally appropriate ways. This type of outreach draws AI/ANs into treatment more readily than outreach targeted at the non-AI/AN population. In addition, the clinic offers traditional healing services certain days of this week, which attracts elders to the clinic. Once elders come in to the clinic for traditional healing, they are often more open to learning about other medical services and programs for which they may be eligible. The Executive Director noted that sending flyers and manuals is not a viable or effective communication method in the AI/AN community.
- Visibility and Word of Mouth. Visibility and word of mouth have also been important in increasing enrollment in the public programs. The fact that outreach workers go out into the field increases the visibility of the clinic within the community, and word of

mouth from current patients has helped to increase the number of AI/AN in Detroit who use the clinic. As more individuals hear about the clinic and come in to the clinic for services, outreach staff can work with these individuals to apply for programs relevant to their needs. The clinic has also made its presence known in the community by organizing health fairs or health booths at tri-city pow-wows. Participation in these pow-wows is important because a cross-section of AI/ANs attend, representing diverse Tribes and communities, which helps spread information about the clinic to a farther-reaching audience.

Security office, which has been very successful in increasing Medicare enrollment, particularly among those qualifying under Social Security Disability Income (SSDI). Because the SSDI application process is complicated and lengthy, few people are persistent enough to complete the application process without help. The clinic sponsors weekly application assistance, where Social Security representatives are available on-site to assist with the application process. In addition to helping with paperwork, these Social Security representatives work with individuals to identify routes for establishing eligibility.

The Executive Director suggested that the following strategies would likely increase AI/AN enrollment in the public insurance programs in the Detroit urban area if they were implemented:

- Large, well-trained outreach team. The Executive Director identified a large, well-trained outreach team as the most useful method to increase enrollment in Medicaid, SCHIP, and Medicare at the Detroit clinic. While the clinic already employs a staff of outreach workers, the director suggested that funds to hire additional trained clinic staff and additional program training for existing clinic staff would increase program enrollment. She felt that they need additional, trained staff to be able to provide the needed outreach and assistance to their patients. The key to reaching eligible AI/ANs, as well as convincing them and assisting them to enroll, is having well-qualified outreach workers to provide the necessary one-on-one interaction
- **More Patient Benefits Staff.** Increased patient benefits coordinator staff would be helpful for patient program education and enrollment assistance. Once an increasing number of patients are registered for programs, she believes these extra positions would pay for themselves. While the clinic could use its FQHC money to hire additional patient benefits coordinators, they would need the money up front to do so.

#### Other Issues

The Executive Director discussed several issues that, while not directly related to enrollment barriers, pose problems for the clinic. Both the evolution of managed care and the increasing cost of prescription drugs have had a strong impact on the clinic.

As a small clinic with limited staff and funds, it has been a burden for the clinic to adapt to the Medicaid/MIChild managed care environment, and little training and technical assistance

from the local, State, or Federal government has been forthcoming to ease this transition. As an FQHC, the clinic survives in part on grants. Currently, the Executive Director researches and writes these grants herself. This was a difficult job before managed care. With the advent of managed care, it has become even more challenging, as she must conduct extensive research to gain an understanding of Medicaid, SCHIP, and Medicare reimbursement issues with respect to the grants she pursues. Funds for more staff to help her with grant writing or a professional grant-writer on staff would help her to both obtain more funding, and to increase staff knowledge of reimbursement issues.

Second, the transition to managed care has also required new billing systems that are equipped to handle third-party reimbursement. While the clinic's billing system, HealthPro, is automated, the clinic staff is under-trained on the software. This is due partly to the difficulty of finding skilled employees and partly to the fact that there is not enough knowledgeable staff to adequately train other staff on the billing system. Again, the clinic faces this stress because of the transition to managed care.

The director also perceives that the State has been forceful in encouraging AI/AN families to enroll in Medicaid managed care, even though it is not mandatory for AI/AN Medicaid recipients. Many AI/ANs do not understand they have the option of choosing, or not choosing, a managed care plan. Once enrolled in a managed care plan, they fear they will lose Medicaid altogether if they disenroll from that plan. As a result, they are often reluctant to disenroll, even if they would like to. Instead, they choose to use the clinic, which cannot receive reimbursement when it is not designated as the primary care site for a patient.

A related point is that it is difficult to for the urban clinic to obtain reimbursement when services are rendered at IHS or Tribal health facilities. Currently, the clinic subcontracts with four HMOs. The capitation rates, however, for the contracted HMOs are very low. In fact, the clinic often does not even receive a check from any of the HMOs at all. According to the Executive Director, this is due in large part to the fact that many AI/ANs who are in a Medicaid HMO would rather receive care at the clinic than at their assigned provider's office because of cultural reasons, because the clinic does not charge co-payments, or because of the persistent stigma associated with public assistance programs. But, if a patient is enrolled in an HMO but chooses to receive services at the urban Indian clinic, the clinic cannot bill for any of these services. Also, it costs the clinic a great deal to treat HMO patients, creating more paperwork and referrals, a need for more training, and more qualified, college-educated staff who are able to develop the knowledge necessary to use the required software systems. As a result, while the clinic is supposed to receive reimbursement from the contracted HMOs, these contracts in reality shift a high percentage of the costs of managed care back to the clinic.

The Executive Director noted that while managed care money may have helped other care systems, it has not spread proportionally to AI/AN health care systems. In fact, some urban Indian health clinics do not even have enough resources or strong enough infrastructure to provide direct medical services to its clients due to the complexities of administering managed care contracts. Instead, these clinics end up serving as a source of health care information and referral. She expressed the opinion that if the State were to invest more in AI/AN delivery systems, the State would benefit in the long run. As it stands, the State's health care system will have to absorb the costs of AI/ANs later in their lives because they may be sicker and require

costlier treatment than if they had received preventive care. The director feels that the failure of Michigan to offer good models for urban Indian health programs has, in itself, caused harm by making it difficult for people to receive care and difficult for the clinic to provide care within the boundaries of managed care regulations. She would like to see a model of care that funds the clinic directly, rather than requiring third party reimbursement.

The cost of prescription drugs for chronic health and mental illness also has hit the clinic hard due to the health status of the urban population it serves. A large percentage of the AI/ANs living in Detroit suffer from poor health and mental illness, a phenomenon she believes is common in urban Indian populations. Generally, urban AI/ANs not only share the same health problems as the general AI/AN population, but their health problems are exacerbated by mental and physical hardships. She believes that urban AI/AN youth also face problems at a higher rate than their non-Indian counterparts. They have a greater risk for serious mental health and substance abuse problems, suicide, increased gang activity, teen pregnancy, abuse, and neglect. In a recent instance, the Centers for Disease Control and Prevention became involved in a hepatitis outbreak involving numerous fatalities associated with IV drug use in a young urban Indian population. She noted that recent studies of the urban Indian population documents the fact that poor health status and the lack of adequate health care services are serious problems for most families. She further stated that this poor health status might be tied to the effects of practicing native traditions in an urban setting.

#### FINDINGS: OTHER ORGANIZATIONS

#### **Covering Michigan's Kids**

#### Overview

Michigan's RWJF pilot project, Covering Michigan's Kids (described earlier in the report), had a particular component targeted at AI/AN children in the Upper Peninsula. Some of the barriers pilot project outreach workers encountered and the outreach strategies the pilot staff successfully employed were discussed in the site visit's interview with the Senior Associate for the pilot project's Program and Policy Development and the Outreach Coordinator for the Upper Peninsula

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

- Many AI/ANs will decide to enroll or not enroll in a program based on the rapport an outreach worker is able to build with the individual. The way an outreach worker dresses can have a tremendous effect on the way their message is received. Formal business attire can very quickly and quite effectively alienate the very people who need the most assistance. Although to some it may seem counterintuitive, "dressing down" can enhance both the rapport of the outreach worker and the credibility of the message they are trying to convey.
- Some Tribes insist that members who are seen at IHS facilities apply for SCHIP and/or Medicaid; others are not as strict with this requirement. In fact, one Tribe insists that the

- member must show a formal letter of denial from the State Medicaid or SCHIP office prior to receiving services at the IHS facility.
- Medicaid data generated by the State is often out of date. Local outreach workers do not
  have access to enough detailed information to make targeted follow-up contacts when
  enrollment anniversary dates approach. Presumptive eligibility, although an effective
  enrollment tool, also limits the amount of data collected and thus, reported.

#### Strategies To Increase Enrollment in Medicaid and SCHIP

- **Self-Declaration of Income.** Pilot project staff interviewed believe that self-declaration of income on Medicaid and MIChild applications has been the State's most successful strategy for increasing program enrollment among all State population groups. They said this operational decision was made because for many in the target populations, income often changes from month-to-month.
- Streamlined Application Process. One particular effort of the pilot project was to use the streamlined joint Healthy Kids/MIChild application soon after its development by a State Steering Committee. The application was also modified to allow AI/ANs to identify themselves, helping to facilitate their cost sharing exemption. Interviewed pilot project staff also stated that the creative use of white space on the form helps to make it look less intimidating and much easier to read. The income verification section and documenting requirements were also removed, as was a question about whether the father was still living in the home.

#### **DISCUSSION**

Overall, Michigan site visit interviewees consider under-enrollment in Medicaid, MIChild and Medicare Savings Programs as only a low to moderate problem for Reservation-based AI/ANs, while under-enrollment in Medicare does not appear to be a significant problem. The two Tribes the site visit team met with, however, both benefit substantially from revenues earned from casino and non-gaming businesses and have been able to use these revenues to strengthen health care services. In contrast, the urban area interviewees perceive a serious under-enrollment in all of the public insurance programs among urban AI/ANs in the Detroit area.

Despite low to moderate under-enrollment for Reservation-based AI/ANs, interviewees still cited several barriers to enrollment in Medicare, Medicaid and MIChild. Urban-area-based interviewees also cited a number of program enrollment barriers, including:

- Limited outreach to potentially eligible Tribal members. This lack of outreach outside of Tribal or urban area AI/AN health clinics results in a general lack of knowledge and understanding of the programs and their benefits for AI/ANs. As such, there is little motivation for them to enroll. In addition many of the Tribal health staff interviewed are not familiar with the programs and, therefore, are not able to provide accurate information to clinic users who may be eligible.
- Lack of incentive to enroll. Among those AI/ANs who are aware of the programs, many choose not to enroll because they feel they already have access to Tribal health services

and therefore perceive no added benefit to enrolling. Some also believe that because the Federal government has promised them health care that they should not have to enroll in programs intended for the non-AI/AN population population or for individuals who fall within certain income guidelines. Many AI/ANs also have a general feeling of mistrust towards the government. All of these factors combined result in disincentives for members to enroll.

- Perceived bias and discrimination. All interviewees Tribal, urban area, and State agencies stated that many AI/ANs feel they have been discriminated against when visiting County FIA offices. This, coupled with the stigma that AI/ANs associate with welfare programs, often creates an additional barrier to the enrollment process. Despite the availability of the applications on-line and at locations other than an FIA office, many AI/ANs continue to visit FIA offices for a variety of reason. First, many AI/ANs are not aware that there are alternate methods to applying for the programs other than in person at an FIA office. Second, even for those that know it is not necessary to go into an FIA office and are aware of how to access the application on-line or at a non-FIA location, not all are able to fill out their applications without one-on-one assistance. Because the applications bears the FIA name, because they may not know where else to seek help, or because AI/ANs traditionally prefer one-on-one interaction, interviewees said that many AI/ANs feel they need to go into an FIA office to obtain help in filling out the application.
- Lack of reliable transportation for Tribal members. Lack of transportation prevents Tribal members from being able to travel to County FIA or local Social Security offices to enroll in the programs, which many believe they must still do. Other AI/ANs know that they can apply for a program by mail or on-line and have the ability to complete the application one of these ways, but are still hesitant to enroll because they know that they do not have the ability to secure transportation to actually access the program's benefits. The transportation barrier is particularly exacerbated when AI/ANs who are not aware that they can opt out of Medicaid/MIChild managed care fail to specify that they want to opt out at the time of enrollment and are automatically assigned to a managed care provider. Members may not want to go to that provider or that provider may be geographically inaccessible to them given the extent of their access to transportation.
- Federal Trust Responsibility. According to interviewees, many AI/ANs perceive that the Federal Trust Responsibility implies that all AI/ANs should have access to medical care through the IHS based on their status as a Tribal member. They should not have to prove eligibility for services by filling out enrollment forms that may require income, asset, and social security information, face-to-face meetings with eligibility staff, and periodic paperwork to re-verify eligibility. For many AI/ANs, the requirement to provide such information conveys an attitude of presumed ineligibility to them. Also, enrollment in programs may actually penalize the beneficiary in some cases. Medicare Part B, for instance, imposes a penalty for every year that the beneficiary waits to initiate services after the age of Medicare eligibility. Interviewees said that the concepts of presumed ineligibility and penalties for enrollment are philosophically opposed to the Federal Trust Responsibility, which is perceived to guarantee health care without the need for coping

with the bureaucracy of public insurance programs designed for the non-AI/AN population.

- Perceived stigma. According to those interviewed, the persistent stigma associated with the use of Medicaid and SCHIP programs is also an issue. Medicaid and SCHIP eligibility are based on income criteria and viewed by some as welfare programs. Many AI/ANs do not want to accept health care through a means-tested program intended for low-income populations when they believe that the obligation of the Federal government is to provide health care to them based on their AI/AN status. While the resulting health care may be the same whatever the source and whatever the funding mechanism, the financial origin of care is an issue of principle and pride for many AI/ANs. Interviewees said they are accustomed to receiving services based on their status as a member of a Tribe, which is a source of pride. Once they are required to enroll in a public health insurance program, income and socioeconomic status become part of the health care delivery system. While this may be common in the non-AI/AN population, it is not as familiar or acceptable a concept in Indian culture, according to interviewees.
- Income fluctuation. Health staff from several clinics stated that it is often difficult for AI/ANs to qualify or remain qualified for Medicaid because the program divides annual income by twelve months and averages across months. Therefore, while an individual may be eligible for Medicaid eleven months out of the year, their income for one month averaged with those other eleven months may make them ineligible for the whole year.
- Medicare Part B premium. Elders who did not sign up for Medicare Part B during their initial eligibility period present a financial challenge for Tribal and urban clinics. Many AI/ANs feel that they are not able to afford Part B premiums. When they choose to postpone enrollment in Part B and then enroll later, not only do they pay a penalty that accrues every year, but they also present a financial barrier for the clinics. When these members access Contract Health Services, the clinic is not able to bill Medicare for these services. While the Medicare Savings Programs are a solution for some, other elders do not qualify for any of these programs because of incomes above the eligibility thresholds.

Based on the reported enrollment barriers, key recommendations provided by the interviewees include:

• **Program Training**. Almost all of those interviewed agreed there is a need for more State-based training to increase program awareness and information for Tribal and urban health clinic staff members and their ability to identify eligible members and facilitate enrollment. This training should include regular and frequent training sessions that keep Tribes informed of impending policy and program changes. Although the MDCH mentioned that training is currently in place, all interviewees indicated the need for more. Training could also include assistance in developing/implementing effective identification and screening tools for identifying potential eligible AI/ANs, either at the point of entry into a Tribal or urban health facilities on a regular basis. Both Tribal and urban clinic staff interviewed have such systems in place, but mentioned they would like

to strengthen and improve these systems to ensure identification of all potentially eligible.

- Outreach and Education. Nearly all interviewees agreed that there is a need for more consumer and community outreach and education about all of the programs. The majority of the Tribal members do not understand that enrolling in these programs will result in increased financial resources, or more efficient use of Tribal resources, and will benefit their Tribe as a whole. Tribal staff felt that if members understood this concept better, they might be more motivated to enroll. All clinic staff interviewed both in Tribal and urban facilities said they could benefit from additional resources to hire more Patient Benefits Counselors and CHRs, which would support more one-on-one assistance both within and outside of health facilities to eligible AI/ANs. Benefits counselors and CHRs could spend more time educating AI/AN communities about the programs and the benefits of enrolling, assisting with transportation issues, and facilitating and providing follow-up with enrollment and redetermination processes.
- Relationship building between Tribes and the State/FIA offices. Those interviewed emphasized the importance of developing and maintaining good relationships with State and County offices. Some also mentioned that increasing the number of FIA outreach workers in Michigan (currently, not all counties have an outreach worker), particularly designated Indian Outreach Workers, would be a good strategy for increasing enrollment.
- On-site determination. Tribal staff from the Sault Ste. Marie Health Center suggested that their ability to determine eligibility on-site (either by their own staff or by a County FIA eligibility worker) would likely result in a marked increase in Medicaid enrollment.

## APPENDIX IV.A: MICHIGAN SITE VISIT CONTACT LIST

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#### **CHAPTER V. MINNESOTA**

#### **BACKGROUND**

#### Overview

This Case Study Report presents background information and findings from a three-day site visit to Minnesota conducted from October 9 through October 11, 2002. The site visit team consisted of Mary Laschober (Site Coordinator), Sally Crelia, and Erika Melman of BearingPoint, and Rebecca Baca of Elder Voices, a consultant to the project. The team visited the Fond du Lac and Mille Lacs Reservations (both located in the central eastern part of the State), and organizations in the Minneapolis/St. Paul urban area. Interviews were conducted with the Great Lakes Inter-Tribal Epidemiological Center, the Bemidji Area Office of the Indian Health Service (IHS), Minnesota Board of Aging's Indian Elder Desk, Minnesota's Department of Human Services, Tribal Health Directors and health clinic staff that included patient benefit coordinators, social workers, eligibility caseworkers, and Contract Health Services, Title VI Senior Services Directors, Tribal members on the Fond du Lac and Mille Lacs Reservations, an Elder Advocate of the Leech Lake Elders Division, housing manager of the Elders Lodge in St. Paul, staff from the Minneapolis Indian Health Board, the administrator of the Hennepin County Medical Center, and the program manager for the Senior Linkage Line and Health Insurance Counseling (Metropolitan Area Agency on Aging).

An earlier version of this Case Study Report was reviewed by the CMS Project Officer and other CMS staff for accuracy and clarity. Subsequently, a Draft Case Study Report was sent to each of the Minnesota organizations that participated in the site visit, with a request that the draft be reviewed for accuracy so that comments and additions could be incorporated into the final Case Study Report. Follow-up telephone contacts were made with all of the above mentioned organizations. Comments and corrections were received from the director of the Minnesota Board of Aging's Indian Elder Desk, Fond du Lac Tribal health staff, and Mille Lacs Tribal health staff.

The comments and recommendations contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or the feasibility of the recommendations. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services (CMS), the Indian Health Service, or the State.

#### Minnesota AI/AN Population and Location

Minnesota has several densely-populated urban areas but is largely a rural State, with about one-third of the State's population living in rural counties. Minnesota's 2000 population was approximately five million people, of whom 1.1 percent, or roughly 55,000, identified themselves as AI/AN. Almost one-fourth of Minnesota's AI/AN population lives on one of the 11 Indian Reservations in the State, which together comprise about 5 percent of Minnesota's

97 http://mn.profiles.iaState.edu/census/, accessed January 31, 2003.

<sup>&</sup>lt;sup>96</sup> http://mn.profiles.iaState.edu/, accessed January 31, 2003.

land mass. The Tribal affiliation of seven of these Reservations is Ojibwe (also called Anishinabe or Chippewa); the other four are Dakota (also called Sioux). 98

Approximately one-third of Minnesota's AI/AN population lives in the central city areas of Minneapolis and St. Paul with an additional 15 percent living in the Twin Cities suburbs, accounting for 1 percent of metro area residents. An estimated 25,957 AI/ANs lived in the Seven-County Metro Area in 1997. Most AI/ANs living in the metro area live in census tracts where they account for less than 2.5 percent of the population. However, AI/ANs account for almost 50 percent of the population in one census tract in South Minneapolis in the area that contains Little Earth, the AI/AN controlled housing program. Twin Cities area AI/ANs have ties with Minnesota Reservations as well as AI/ANs living in North and South Dakota and Wisconsin.<sup>99</sup>

About 38 percent of the AI/AN population in Minnesota is under the age of 18, which is almost 15 percentage points higher than the overall Minnesotan population under age 18. Approximately one-third of AI/AN children live with both parents in a married couple family, but nearly one-half live in single parent homes. Officially, 10 percent of AI/AN children live with blood relatives other than a parent, such as a grandparent or aunt. Another six percent live with non-relatives in foster care, group quarters, or institutions. <sup>101</sup>

Poverty is prevalent throughout Minnesota's AI/AN population. Most AI/ANs receive less than one-half of the income of White households, with 44 percent estimated to be living in poverty. According to the 1990 U.S. Census, 49 percent of AI/ANs in Minnesota made less than \$15,000 compared with 23 percent of all Minnesotans. This is due, in part, to the high level of unemployment among members of this population, estimated at 38 percent in 1999 by the Bureau of Indian Affairs (BIA). The BIA estimated that another 30 percent of Minnesota AI/ANs were employed but living below poverty guidelines. Education levels are also lower, with 62 percent of Minnesota AI/ANs having a high school diploma or higher education in 1990 compared with 82 percent of all Minnesotans. Poverty is also more prevalent among the AI/AN population than other minorities in Minnesota, especially with regard to children. According to the 1990 Census, 12 percent of all children living in Minnesota lived in poverty. Of AI/AN children, however, 55 percent lived in poverty, compared to 50 percent of African American children, 32 percent of Asian Pacific children, and 26 percent of Hispanic children.

Additionally, AI/ANs in Minnesota experience significantly higher rates of disease and premature death than the overall Minnesota population. Large disparities exist in rates of infant mortality, high birth weight births, injury and violence, diabetes, cardiovascular disease, cancer,

104 Ibid.

<sup>98</sup> http://www.health.State.mn.us/divs/chs/pdf/gdlinebkgrd7.pdf, accessed April 18, 2003.

<sup>99</sup> http://www.senate.leg.State.mn.us/departments/scr/report/ bands/TC.HTM, accessed January 29, 2003.

<sup>100</sup> http://mn.profiles.iaState.edu/census/, accessed January 31, 2003; The Great Lakes EpiCenter. *Community Health Profile Minnesota, Wisconsin & Michigan Tribal Communities 2001*. Great Lakes Inter-Tribal Council, Inc., 2001.

http://www.cdf-mn.org/ChildHealthMN.htm and http://www.airpi.org/livingar.html, accessed January 15, 2003.

<sup>&</sup>lt;sup>102</sup> The Great Lakes EpiCenter, 2001.

<sup>103</sup> Ibid.

<sup>105</sup> Ibid.

<sup>106</sup> http://www.cdf-mn.org/ChildHealthMN.htm and http://www.airpi.org/livingar.html, accessed January 15, 2003.

and other conditions.<sup>107</sup> For example, compared to the White population, the diabetes death rate is 4.9 times higher among AI/ANs, and complications from the disease are greater for AI/ANs in Minnesota: lower-limb amputations are four times greater for AI/ANs compared with White individuals with diabetes and diabetes-complicated birth is five times greater in AI/ANs.<sup>108</sup> Eliminating health disparities is a national (*Healthy People 2010*) and State (*Healthy Minnesotans 2004*) goal. In 2001, the Minnesota legislature provided specific funds to implement the Eliminating Health Disparities Initiative.<sup>109</sup>

#### AI/AN Health Services in Minnesota

The Bemidji Area Office of the IHS, located in Bemidji, Minnesota, provides health services to about 93,000 AI/ANs residing in five States with Tribal facilities in Minnesota, Wisconsin, Michigan and Indiana, and urban centers in Minnesota, Wisconsin, Michigan, and Illinois. Ojibwe (Chippewa) Indians are the most numerous of the 34 Federally Recognized AI/AN Tribes served by the Bemidji Area. Still occupying areas today where they earlier settled are the Ottawa, Potawatomi, Menominee, Ho-Chunk, and Sioux. Only the Oneida, a member of the Iroquois Confederacy of upState New York and the Stockbridge-Munsee Mohican Band (originally from Massachusetts) were resettled in the area from greater distances.

The Bemidji Area office supports two IHS-operated short-stay hospitals, two health centers, and five health stations in three IHS Service Units. The Bemidji Area is unique, however, in that nearly all of the annual IHS funding allocation (97.4 percent as of FY 1998) is distributed among the Federally Recognized Tribes through contracts and self-governance compacts. Each Tribe contracts or compacts with IHS for health services ranging from outreach and contract health care to fully comprehensive health delivery systems, including environmental health services and sanitation facilities and health facilities construction.

Under Public Law 93-638 contracts, Bemidji area Tribes operate 24 health centers and 33 health stations. Health centers are open 40 or more hours per week with primary care providers on staff who can also offer comprehensive ancillary services. Health stations are open less than 40 hours per week, some with primary care providers and limited ancillary services. The most common arrangement for AI/ANs living on a Reservation in Minnesota is to have clinical services provided on the Reservation by the IHS or the Tribe, with contract health services available in local communities for more complex care. The provider of the tribe of tribe of the tribe of tribe of the tribe of tribe of the tribe of the tribe of tribe of the tribe of tribe of the tribe of tri

In addition to providing health care for AI/ANs in the Bemidji Area through IHS and Tribal facilities, a number of public health care programs include funding specifically set aside to meet the needs of AI/ANs. For example, the State's Consolidated Chemical Dependency Treatment Fund formula includes allocations for AI/ANs living on and off Reservations. The

<sup>&</sup>lt;sup>107</sup> The Great Lakes EpiCenter, 2001.

http://www.health.State.mn.us/ommh/diabetes.html, accessed April 18, 2003.

<sup>109</sup> http://www.health.State.mn.us/divs/chs/pdf/gdlinebkgrd7.pdf, accessed April 18, 2003.

The population is based on the official 2001 Headquarters User Population data of Federally Recognized Indians who use IHS services (http://www.ihs.gov/FacilitiesServices/AreaOffices/Bemidji/index.asp, accessed January 15, 2003

http://www.ihs.gov/FacilitiesServices/AreaOffices/Bemidji/Bem.asp, accessed January 22, 2003.

<sup>112</sup> http://www.senate.leg.State.mn.us/departments/scr/report/bands/RESTABLE.HTM, accessed January 22, 2003.

Federal Alcohol, Drug Abuse and Mental Health block grant includes an allocation for AI/AN services. The State law establishing community health boards also authorizes special grants to these boards to provide services to AI/ANs living off Reservations. The grants are administered by the Minnesota Department of Health and are awarded on a competitive basis. Current grantees serve the Bemidji area and the cities of Duluth, Minneapolis, and St. Paul. 113

#### **Overview of Minnesota State Government**

Public Law 280, passed in 1953, gave Minnesota and certain other States criminal and civil jurisdiction in Indian Country. It also provided a mechanism by which the States could assume permanent jurisdiction over Indian nations. All Tribes in Minnesota are subject to this law except for Red Lake Reservation. The Red Lake Reservation is the only "closed" Reservation in Minnesota, meaning that this Tribal land was never allotted and continues to be held in common by Tribal members. 114

In 1963, Minnesota became the first State to create an Indian Affairs Council as an official liaison between the State and the State's 11 Tribal Reservation governments. The Council membership consists of the elected Tribal chair of the 11 Reservations throughout the State, two at large members from Federally Recognized Tribes not based in Minnesota but who are Minnesota residents, and several ex officio members representing State agencies. The Council also provides a forum for, and advises the State government on, issues of concern to urban AI/AN communities through the Urban Indian Advisory Council as an active subcommittee of the Indian Affairs Council. The Indian Affairs Council plays a significant role in the development of State legislation. It also monitors programs that affect Minnesota's AI/AN population and Tribal governments. Additionally, Minnesota's Department of Human Services (DHS), which oversees the State's health care programs, employs a Native American liaison, which has been filled by an American Indian since 1994.

Minnesota State government includes the Minnesota Board on Aging (MBA), established under DHS in 1956 (more description is provided below). The MBA administers funds from the Older Americans Act that provide a spectrum of services to seniors, including Senior LinkAge Line®, Insurance Counseling, and more. MBA includes an Indian Elder Desk that serves AI/AN elders on the State's 11 Reservations and in urban communities. An American Indian has staffed the Indian Elder Desk since 1994. Additionally, begun in 1999 as a partnership among Minnesota's AI/AN communities and the MBA, the Wisdom Steps program encourages Tribal elders to take simple steps toward better health. The program was designed by and for Tribal elders and others in AI/AN communities.

115 http://www.auditor.leg.State.mn.us/fad/1995/fad95-48.htm, accessed April 18, 2003.

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<sup>113</sup> http://www.senate.leg.State.mn.us/departments/scr/report/bands/, accessed January 23, 2003.

<sup>114</sup> http://www.indians.State.mn.us/tribes.html, accessed April 18, 2003.

<sup>&</sup>lt;sup>116</sup> Interview with Mary Snobl, Minnesota Board on Aging Indian Elder Desk; Wisdom Steps Coordinator, October 2002.

http://www.mnaging.org/ services/iep.html, accessed January 29, 2003.

<sup>&</sup>lt;sup>118</sup> Interview with Mary Snobl, Minnesota Board on Aging Indian Elder Desk; Wisdom Steps Coordinator, October 2002.

http://www.wisdomsteps.org/wisdomsteps.htm, accessed January 29, 2003.

Minnesota's DHS oversees four publicly funded health care programs in the State as described previously. DHS employees work closely with employees from Minnesota's 87 counties, which provide most of the direct services to Minnesotans in need. In addition to application simplification, including the ability to mail in applications, the State has conducted other efforts designed to increase AI/AN enrollment. For example, two 2003 recipients of State outreach grants directly target AI/ANs. A \$125,000 grant to the Lake Superior Community Health Center, which includes the Bois Forte Reservation in its service area, provides for screening, referrals, public education, and application assistance. The Red Lake Band of Chippewa received a \$28,000 grant to provide outreach and application assistance on the Red Lake Reservation. 120

According to the State, there is a great deal of ongoing interaction between DHS staff, Tribal directors, and Tribal health directors from each of the 11 Federally Recognized Tribes in Minnesota. For instance, Tribal health directors meet quarterly to discuss planning, implementation and other policy issues related to Minnesota's health care programs. DHS has several staff assigned specifically to serve as liaisons to AI/AN Tribes.

The Minnesota Board on Aging (MBA), under DHS, is the gateway to services for seniors and their families in Minnesota. MBA administers funds from the Older Americans Act that provide a spectrum of services to seniors, including Senior LinkAge Line®, Insurance Counseling (although no Federal Insurance Counseling Agency funds are dedicated to Indian County), and more. First established in 1956, the MBA works closely with its Area Agencies on Aging, which are located throughout the State, to provide services that seniors need. MBA includes an Indian Elder Desk that serves all AI/AN elders living in the State. The Indian Elder Desk focuses on building awareness of, and improved accessibility to, services for Indian elders; training and educating Indian elders and their communities about aging programs; weaving a web of support for Indian elders using a variety of resources, including national, Tribal, State and regional; providing information about available Indian and non-Indian resources for the aging. including the "Indian Elder Community Resource Guide;" and helping communities develop model programs that help Indian elders. For example, the Indian Elder Desk has worked with the Mille Lacs Band of Ojibwe to create "Migizi Elderly Services," which developed service directories for each of their three government services; with Indian elders in Duluth, Minneapolis, and St. Paul to build the "Urban Indian Elder Services Network" to improve communication among agencies providing services to urban Indian elders and to encourage seniors to be active in program development; and participates in the organization of the Midwestern AI/AN Elder Program Network.<sup>121</sup> The MBA also helps administer the Wisdom Steps program, described previously.

#### **Minnesota State Medicaid Program**

More than 400,000 Minnesotans receive health care coverage through Minnesota's Medicaid program (Medical Assistance (MA))<sup>122</sup> which is the largest of the State's three health

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<sup>&</sup>lt;sup>120</sup> Comments from CMS, March 2003, based on language obtained from the approved Minnesota SCHIP State plan. <sup>121</sup> http://www.mnaging.org/services/iep.html, accessed January 29, 2003.

<sup>&</sup>lt;sup>122</sup> A separate report being submitted under this project's contract will address the number of AI/ANs – children and adults – who receive coverage through MA.

care programs that include MA, MinnesotaCare, and General Assistance Medical Care (GAMC). 123 The Federal and Minnesota governments jointly fund the MA program, local County governments determine program eligibility, and DHS oversees the three programs. A wide variety of services are covered under the MA program including physicians' services, inpatient and outpatient hospital care, hospice care, dental services, and prescription drugs. 124

Eligibility requirements consist of meeting income and asset guidelines, being a Minnesota resident, and being a U.S. citizen or "qualified" non-citizen. For example, some American Indians born in Canada are eligible under the same conditions as U.S. citizens. <sup>125</sup> MA eligibility categories include pregnant women whose income is at or below 275 percent of the Federal Poverty Level (FPL), children below age 2 living in households with incomes at or below 275 percent of FPL, children ages 2-18 with household incomes at or below 170 percent of FPL, children ages 19-20 with household incomes at or below 100 percent of FPL, adults with children in households at or below 100 percent of FPL, and aged, blind, or disabled persons at or below 100 percent of FPL. 126 Applicants who make more than the MA income limits may still qualify if they meet "spend down" criteria in which their medical bills exceed the difference between their income and the MA standard. There are no asset limits for children under age 21 and pregnant women; asset limits equal \$3,000 for a single person and \$6,000 for a household of two, plus \$200 for each additional household member for people 65 or older, who are blind, or who have disabilities; and \$15,000 for a household of one and \$30,000 for a household of two for families with children. 127

Applicants complete a four-to-six page Minnesota Health Care Programs application, which can be mailed or brought to their County human services agency. The application, available in 10 languages, can be used for MA, MinnesotaCare (described below), GAMC, and the State's Prescription Drug Program. <sup>128</sup> As of December 2002, 55 percent of the 433,294 MA recipients were children and 45 percent were adults. 129

MA recipients receive services from fee-for-service providers or prepaid health plans through the Prepaid Medical Assistance Program Plus (PMAP+), depending on the recipient's resident County. Under a Medicaid 1115 waiver since 1995, PMAP+ provides comprehensive health coverage to approximately 170,000 low-income and medically needy children, families, and seniors in 69 of the 87 counties in the State through contracts with managed care

<sup>123</sup> GAMC is a State/County-funded, County-based program that covers low-income individuals who do not qualify for MA. The vast majority of beneficiaries are adults between ages 21 and 64 without dependent children (http://medicaidmanagedcare. naralny.org /States/mn.htm, accessed April 18, 2003. http://www.dhs.State.mn.us/healthcare/, accessed January 29, 2003.

http://www.dhs.State.mn.us/HealthCare/reportsmanuals/manualCounty/chapter06.htm#0906.03.11.21, accessed January 30, 2003.

http://edocs.dhs.State.mn.us/live/DHS-3461-2002-ENG.pdf, accessed April 19, 2003.

http://www.dhs.State.mn.us/healthcare/asstprog/mmap.htm, accessed January 29, 2003.

<sup>&</sup>lt;sup>128</sup> The State's Prescription Drug Program helps Minnesota seniors and people who are certified as disabled pay for prescription drugs. Those who qualify pay the first \$35 of their prescription drug costs each month and the Prescription Drug Program pays the rest. As of December 2002, 84 percent of the 6,345 enrollees were 65 or older and 16 percent were under age 65 (Minnesota Department of Human Services, HCEA Division, http://www.dhs.State.mn.us/HealthCare/enrollment/, accessed January 29, 2003).

<sup>&</sup>lt;sup>129</sup> Minnesota Department of Human Services, Reports and Forecast Division, http://www.dhs.State.mn.us/ HealthCare/enrollment, accessed April 19, 2003.

organizations (MCOs). Enrollees may request to change MCOs one time in the first year of enrollment and thereafter during a 30-day open enrollment period during the fourth quarter of the year. A recent Minnesota law allows any AI/AN – including those enrolled in PMAP+ – to receive health services at any Tribal clinic, for which the Tribal clinic receives Medicaid payment based on an all-inclusive rate negotiated by the CMS and IHS. Additionally, any Tribal clinic can be a primary care provider for AI/ANs enrolled in the PMAP+ program.

#### **Minnesota SCHIP Program**

Minnesota has a Medicaid expansion SCHIP program that uses Federal SCHIP funds to provide health care coverage for children up to age 2 living in households with incomes between 275 and 280 percent of the FPL (children below 275 percent of FPL are eligible for MA). Moreover, Federal SCHIP monies fund several health services initiatives that include mental health screenings of children in the court system, outreach and mental health screenings for homeless children, comprehensive services for children with special health care needs, and family planning services. The State also uses SCHIP funds through a Section 1115 demonstration to cover uninsured parents and caretaker relatives of Medicaid and SCHIP eligible children living in households with incomes between 100 and 200 percent of FPL. Additionally, Minnesota created a seamless system by integrating the SCHIP program with the State's PMAP+ program to form MinnesotaCare, administered by Minnesota's DHS. All children covered at that time by the State-sponsored Children's Health Plan program were converted to MinnesotaCare. This coverage assures health insurance for children, their parents, and other adults, which helps reduce the rate of uninsured persons living in Minnesota and improves upon State programs.

There are no health condition barriers to MinnesotaCare application, but applicants must meet income and program guidelines to qualify. Additionally, qualifying adults must not have had other health insurance for the past four months or have access to employer-based insurance in which the employer pays at least 50 percent of the insurance premium. There is considerable overlap in income eligibility guidelines for MA and MinnesotaCare and consumers are able to make an "informed choice" about which program to apply. For example, MinnesotaCare is available to adults 21 years old or older who are pregnant or have children in households with incomes at or below 275 percent of FPL. Many pregnant women, therefore, can choose whether they want to apply to MA or to MinnesotaCare. Other MinnesotaCare eligibility categories include single adults and couples 21 years old or older without children whose income is at or below 175 percent of FPL. Children ages 2 through 21 living in households with incomes up to 275 percent of FPL are eligible for MinnesotaCare (and many are eligible for MA). 132

All MinnesotaCare enrollees pay a premium that is determined on a sliding scale, ranging from \$4 to more than \$400 per month, depending on household size, income, and number of people covered. However, Minnesota exempts SCHIP-eligible children who are members of Federally Recognized Tribes from premium payments. MinnesotaCare is funded through

<sup>&</sup>lt;sup>130</sup> Comments from CMS, March and August 2003.

<sup>&</sup>lt;sup>131</sup> Comments from CMS, August 2003.

http://www.dhs.State.mn.us/HealthCare/MinnesotaCare/eligibility.htm, accessed April 19, 2003, and comments from CMS, August 2003.

enrollee premiums, State of Minnesota general revenues, a tax on health care providers, and Federal matching SCHIP dollars. 133

MinnesotaCare covers outpatient medical services, inpatient hospital benefits, orthodontia for children, and transportation services for children and pregnant women to and from medical appointments through PMAP+ providers. As of December 2002, 54 percent of the 153,986 Minnesotans enrolled in MinnesotaCare were adults and 46 percent were children.<sup>134</sup>

#### **DESCRIPTION OF SITE VISIT**

#### Overview

Prior to conducting the site visit, the team contacted Pam Iron (National Indian Women's Health Resource Center, Oklahoma), and Spero Manson (Division of American Indian and Alaska Native Programs, University of Colorado Health Sciences Center), Technical Expert Panel (TEP) members; Dave Baldridge (National Indian Council on Aging (NICOA)), and Ralph Forquera (Seattle Indian Health Board), Project Consultants; Jo Ann Kauffman (Kauffman & Associates), Project Consultant (who also sought suggestions from Glen Safford from the Great Lakes Inter-Tribal Council and Kathleen Annette, Director, Bemidji Area IHS Office); Pam Carson and Ruth Hughes, CMS Native American liaisons in the Chicago CMS Regional Office; and Jenny Jenkins, Assistant to the Area Director for the Bemijdi Area IHS. The team solicited advice on which communities the site visit team should visit in Minnesota, who initial key contacts might be, and which issues specific to the State should be addressed in the study. Interviewees were asked to recommend two Tribes/Reservations and one urban area with a facility that provides direct medical services and to provide background information on the sites recommended. The project team also emphasized that, given that only three days were budgeted for visiting two Reservations and an urban area, travel distances were of some importance.

Advisors strongly suggested the team concentrate on visiting Chippewa rather than Sioux Tribes in Minnesota, as Sioux issues would be addressed during the North Dakota and South Dakota site visits. Additionally, Chippewa Indians are the most numerous of the 34 Tribes served by the Bemidji Area IHS. Because we were advised that it is difficult to avoid gaming in Minnesota, we did not use it as a site selection criterion for Minnesota. Based on our discussions, the project team selected the Fond du Lac Reservation, the Mille Lacs Reservation, and Minneapolis/St. Paul (the Minneapolis Indian Health Board) as visit sites.

Advisors unanimously recommended we visit Fond du Lac. Fond du Lac Ojibwe was characterized as a fairly progressive Tribe that operates its own health facilities under the Indian Self-Determination Act of 1975 (P.L. 93-638 as amended), and has developed model elder and health services programs. The Tribal health director, Phil Norrgard, was characterized as being extremely knowledgeable and proactive about AI/AN health services for Fond du Lac as well as for the rest of the State.

<sup>133</sup> http://www.dhs.State.mn.us/HealthCare/MinnesotaCare/default.htm, accessed January 17, 2003.

Minnesota Department of Human Services, Medicaid Management Information System (MMIS), http://www.dhs.State.mn.us/HealthCare/enrollment/, accessed April 19, 2003.

<sup>&</sup>lt;sup>135</sup> For the Minnesota site visit, we did not contact the Covering Kids State director because no Covering Kids State pilot projects focus on the AI/AN population in the State.

While the Mille Lacs Band of Ojibwe also contracts with IHS to run its own health facilities, is fairly progressive, and has successful gaming – similar to Fond du Lac – it was strongly recommended for a site visit because of its uniqueness among AI/AN Tribes in administering its own Temporary Assistance for Needy Families (TANF) and MA programs under a CMS waiver.

Minneapolis/St. Paul was unanimously recommended for the urban area site visit in the State. It ranked 12<sup>th</sup> in the United States in terms of urban AI/AN population. The Minneapolis Indian Health Board (MIHB) has a very good reputation for successful third-party billing and might provide a good model for other Urban Indian Health Centers. Additionally, one of our project consultants had good contacts at a St. Paul residential center for AI/AN elders. Advisers also recommended that we talk with staff at the Hennepin County Medical Center, which is a primary point of referral for the Twin Cities urban area's AI/AN population.

Because the Bemidji Area IHS office and the Great Lakes Inter-Tribal Epidemiological Center were not within feasible travel distances for the three-day site visit, and because we could not schedule a time with the Minnesota Department of Human Services (MA and MinnesotaCare) central office that was compatible with the rest of the site schedules, we interviewed these organizations by telephone following the site visit. The individuals and organizations with whom the site visit team met in Minnesota or conducted follow-up telephone interviews are listed in attached Appendix V.A.

# Description of Fond du Lac Band of Ojibwe

Fond du Lac, a Federally Recognized Tribe 20 miles west of Duluth, Minnesota, has a Reservation population of approximately 3,200. Tribal members live on a total of 100,000 acres, with 17,034 allotted acres and 4,800 Tribally owned acres. According to the 1990 Census, Fond du Lac had the fourth highest number of AI/AN children living outside of the Greater Minnesota metro regions at 520.

Fond du Lac Reservation is one of six Reservations inhabited by members of the Minnesota Chippewa (Ojibwe) Tribe. The Chippewa Nation is the second largest ethnic group of AI/ANs in the United States. <sup>139</sup> Major sources of revenue for Fond du Lac Band members are derived from two Tribally-owned casinos: the Fond du Luth located in Duluth and the Black Bear Casino located near Cloquet. The Tribe and the city of Duluth cooperated in building and

<sup>&</sup>lt;sup>136</sup> Forquera, R. *Urban Indian Health*. Prepared by The Seattle Indian Health Board for The Henry J. Kaiser Family Foundation, November 2001.

<sup>&</sup>lt;sup>137</sup> Subsequent to site selection, but prior to our site visit to Minnesota, project consultants informed us that the MIHB was experiencing significant turmoil and recommended we not visit it. We did try to contact the MIHB prior to our visit, but were not successful. However, we were able to conduct follow-up telephone interviews with MIHB staff following the site visit.

http://www.oakhills.edu/cim/fonddula.html, accessed January 2, 2003.

http://www.fdlrez.com/government.htm, accessed January 16, 2003.

sharing in the profits of the Fond du Luth Casino. Annual revenues are substantial and about one-half of the casinos' employment is Tribal and the rest is comprised of local non-Indians. 141

Tribal human service and health programs located on the Reservation are based in the Tribally operated Min-No-Aya-Win Human Services Center in Cloquet. The Tribe also operates a similar Indian health program in Duluth at the Center for AI/AN Resources (CAIR). Additionally, Mash-Ka-Wisen, located in Sawyer, is the nation's first Indian-owned and operated residential primary treatment facility for chemical dependency. Under a Public Law 93-638 contract with IHS, the Tribal Human Services Division receives about \$2 million a year from the Tribe for mental health, prescription drugs, domestic violence, and other programs. The closest IHS hospitals are at Leech Lake and Red Lake, both approximately a four- to five-hour drive from Fond du Lac. For FY 2001, IHS user population statistics for the Fond du Lac Tribally operated service unit included 8,852 Indian registrants, with 5,218 active Indian registrants and estimated user population.

## **Description of Mille Lacs Band of Ojibwe**

Mille Lacs, a Federally Recognized Tribe located in east central Minnesota, has a Reservation population of approximately 1,150 living on 61,000 acres. <sup>145</sup> Of the total estimated Tribal enrollment of 2,900, 1,094 are age 21 or younger and 272 are elders age 55 or older. The Tribe owns approximately 16,000 acres of land located within four townships on the south end of Mille Lacs Lake. Additional communities exist in Aitkin and Pine counties and three islands. <sup>146</sup> According to interviewees, ownership of only a few small, widely scattered parcels of land often presents difficulties for Mille Lacs in bringing together all Tribal members. However, unlike some more isolated Reservations, Mille Lacs is located on the shores of a large lake with good highway access to the nearby Twin Cities metro area.

The Reservation has a community center, schools, a health clinic, museum, casino/hotel complex and a government center. Mille Lacs owns two casinos. The Tribe distributes very little of the revenues realized, but casino money has made it possible to reduce unemployment to approximately three percent. This is accomplished through jobs in a variety of Tribally conducted programs including a new school. A major benefit of casino revenues is also the Tribe's ability to increase its land base. 147

The Reservation's health program is Tribally run under a Public Law 93-638 contract with IHS. The Mille Lacs Ne-Ia-Shing and Aazhoomog clinics on the Reservation provide mainly primary care and some telemedicine. Secondary and tertiary care is provided through referral to IHS or private hospitals in the Mille Lacs area. The closest IHS hospitals are at

<sup>144</sup> Final User Population Estimates, FY 2001, DHHS Memorandum dated March 1, 2002.

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<sup>140</sup> http://www.indians.State.mn.us/fondlac.html, accessed January 15, 2003.

<sup>141</sup> http://www.oakhills.edu/cim/ fonddula.html, access January 2, 2003.

<sup>142</sup> http://www.indians.State.mn.us/fondlac.html, accessed January 15, 2003.

<sup>&</sup>lt;sup>143</sup> Interviews with clinic staff.

http://www.kstrom.net/isk/maps/mn/millelac.htm, accessed January 2, 2003.

http://www.indians.State.mn.us/millelac.html, accessed January 15, 2003.

http://www.kstrom.net/isk/maps/mn/millelac.htm, accessed January 17, 2003.

<sup>&</sup>lt;sup>148</sup> Interviews with clinic staff.

Leech Lake and Red Lake, both approximately four- to five-hour drives from Mille Lacs. Clinic services are also offered at the East Lake Community Center two days a week and traditional healers come to the Center twice a month. The Center will also soon begin filling prescriptions through a tele-pharmacy machine. Tribal health services include chemical dependency and mental health services. In FY 2001, IHS user population statistics for the Mille Lacs Tribally operated service unit included 2,841 Indian registrants, with 2,164 active Indian registrants and 2,175 estimated user population.

Outside of Mille Lacs Reservation, access to public welfare programs in Minnesota is attained through County human service agencies. The 1996 Federal welfare reform legislation, however, authorized Federally Recognized Tribes to operate the employment and training services component, as well as the income maintenance portion, of MFIP-S (Minnesota Family Investment Program-Statewide, which replaced the Aid to Families with Dependent Children (AFDC) program on January 1, 1998). The Mille Lacs Tribal government has chosen to operate MFIP-S for families with an adult enrolled in the Band who resides in the six County area of Aitkin, Benton, Crow Wing, Mille Lacs, Morrison, and Pine counties. The Tribal government is one of only 12 in the nation that have chosen to assume responsibility for operating an income maintenance program since Tribes were authorized to do so in 1996, according to the Minnesota DHS. Other Minnesota Tribes have expressed an interest in operating MFIP-S but have not yet made a final decision, according to DHS. Since 1999, the Mille Lacs Tribal government has also administered the Food Stamp and MA programs for these clients. The Tribe utilizes the Statewide computer system and State forms for ease of administration. 

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Mille Lacs also has a unique Tribally funded program called "Circle of Health." In existence for about three years, Circle of Health is an endowment fund derived from casino and other successful Mille Lacs Band investments that pays health care premiums, co-payments, and deductibles for all Tribal members, irrespective of income, residence, or source of health insurance coverage (including employer-sponsored coverage).

#### Description of the Minneapolis/St. Paul Urban Area

A number of public health clinics, such as the MIHB and the Model Cities Health Center in St. Paul, provide services to AI/ANs through PMAP+. MIHB staff serves AI/ANs from approximately 25 different Tribes. MIHB is a private nonprofit organization in operation since 1971 with a mission to provide health care services to the AI/AN population as well as the general public. The combined medical, dental, and mental health clinics see some 2,000 patient visits per month. MIHB also administers a WIC clinic, HIV/AIDS management program, and a wide-variety of health education services. MIHD and the MIHD management program, and a wide-variety of health education services.

<sup>&</sup>lt;sup>149</sup> Mille Lacs Band directory.

<sup>&</sup>lt;sup>150</sup> Final User Population Estimates, FY 2001, DHHS Memorandum dated March 1, 2002.

<sup>151</sup> http://www.senate.leg.State.mn.us/ departments/scr/report/bands/, accessed January 23, 2003.

<sup>152</sup> http://www.senate.leg.State.mn.us/departments/scr/report/bands/, accessed January 23, 2003.

During the time of our site visit to Minnesota, the MIHB was experiencing considerable conflict between the administration and staff, with substantial recent turnover in both.

http://www.thecirclenews.org/032002/news1.html, accessed January 25, 2003.

The Elders Lodge of St. Paul, whose staff was interviewed during the site visit, is supported mainly by the Amherst H. Wilder Foundation in St. Paul as an independent living community made up of 42 subsidized one-bedroom apartments. Elders Lodge provides service-enriched housing for low-income adults age 62 and older and people with qualifying mobility impairments. For an additional fee, residents may also arrange home health or personal care, meal delivery, and other services. Elders Lodge is designed with many American Indian themes to welcome its predominantly AI/AN resident population. Of Elders Lodge's residents, about 90 percent are female, 70 percent are people of color, with an average age of 64, and 100 percent have incomes below 125 percent of poverty level. 155

The Metropolitan Area Agency on Aging (MAAA) is one of 14 Minnesota Area Agencies designated and funded by the Minnesota Board on Aging to link people to information; assist community groups and service providers with planning, coordination and development; and improve the quality of life for seniors and their families through local and regional initiatives. In addition to many other programs, MAAA administers Minnesota's Senior LinkAge Line® and the State Health Insurance Assistance Program (SHIP) for the Twin Cities area. <sup>156</sup>

Hennepin County Medical Center (HCMC) is a comprehensive academic medical center and public hospital located in the heart of the Twin Cities of Minneapolis and St. Paul, Minnesota. Their health care campus includes a 360-bed acute care hospital and primary care and specialty clinics; a multi-specialty group practice; the third-largest nonprofit medical research organization in Minnesota; and the Metropolitan Health Plan (Hennepin County's licensed health maintenance organization). HCMC also operates four primary care clinics in Minneapolis and suburban Hennepin County. <sup>157</sup>

# **Description of Other Organizations Interviewed**

The Great Lakes Inter-Tribal Epidemiological Center, located in Wisconsin, is one of six partially-IHS funded Epidemiology Centers (EpiCenters) throughout the United States, serving Tribes in Minnesota, Michigan, and Wisconsin. The Great Lakes EpiCenter is an Epidemiological Cooperative Agreement Project working through the Great Lakes Inter-Tribal Council in partnership with Federally Recognized AI/AN Tribes of Ojibwe, Ottawa, Menominee, Mohican, and Potawatomi. The EpiCenter assists Tribes in the collection, interpretation, and analysis of health information to help them more effectively administer their health programs and plan for healthier communities. <sup>158</sup>

<sup>155</sup> http://www.wilder.org/programs/AffordableHousing/elderslodge.html, accessed January 25, 2003.

<sup>156</sup> http://www.tcaging.org/home.htm, accessed January 25, 2003.

http://www.hcmc.org/, accessed January 25, 2003.

<sup>158</sup> http://www.ihs.gov/medicalprograms/epi/ accessed on January 29, 2003.

# FINDINGS: MINNESOTA MEDICAID AGENCY AND OTHER STATEWIDE AGENCIES<sup>159</sup>

Great Lakes Inter-Tribal Epidemiological Center, Leech Lake Elders Division, Minnesota Board of Aging, Minnesota Department of Health Services

#### Overview

To obtain a statewide perspective on AI/AN barriers to enrollment in the MA, MinnesotaCare, and Medicare programs, we interviewed by telephone two staff from the Great Lakes Inter-Tribal Epidemiological Center, staff in the Bemidji Area IHS office by telephone, and an Elder Advocate of the Tribally-based Leech Lake Elders Division in-person. To obtain the State government's perspective, we also interviewed by telephone the director of the Minnesota Board of Aging's Indian Elder Desk (who is also the Statewide Wisdom Steps coordinator), and several staff from Minnesota's DHS, including the Tribal Relations Representative, Tribal Relations Specialist, Manager of CMS Relations, Manager of Negotiations, Tribal, and Waiver Relations, an Indian Programs Specialist and the Special Assistant to the Director for Chemical Dependency, the American Indian Programs Specialist for Mental Health, and staff from the Health Care Eligibility and Access Division.

According to DHS interviewees, DHS has taken substantial steps over the past decade to improve State-Tribal government relations through the funding and hiring of dedicated American Indian staff (e.g., Native American liaisons, the Board on Aging's Indian Elder Desk), and to provide MA, MinnesotaCare, and Medicare training and education to professionals and consumers across the State. However, those interviewed from the State government said they are aware that greater efforts and resources are needed to address serious AI/AN under-enrollment in these programs. They noted that there is a substantial lack of Tribal and urban AI/AN professionals or lay people who can help with one-on-one application assistance, which they feel is needed to increase program enrollment. Like other States, however, Minnesota is facing significant budget shortfalls.

Statewide organization interviewees also acknowledged that Tribal operation of public benefits programs would greatly improve program enrollment, but, again, said that the lack of funds for Tribes to set up the infrastructure and systems needed to run their own programs, as well as CMS waiver support, are serious obstacles.

Interviewees generally believed AI/AN under-enrollment in MA and the Medicare Savings Programs 160 to be a serious problem Statewide but relatively small problem for

<sup>&</sup>lt;sup>159</sup> Although the Great Lakes Inter-Tribal Epidemiological Center serves Michigan, Minnesota, and Wisconsin, their outreach funds only extend to Wisconsin. Therefore, staff comments are represented in a very limited way in this report as they specifically relate to Minnesota AI/ANs.

The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

MinnesotaCare. They believe that most AI/ANs in Minnesota are aware of Medicare, but do not have detailed knowledge about the program. Barriers to MA, the Medicare Savings Programs, and MinnesotaCare enrollment include resistance to applying in-person at County human services offices due to a lack of reliable transportation and short-term daycare assistance to visit these offices, as well as mistrust of government programs. Although mail-in application is allowed, there is a perception that many AI/ANs do not realize this, or they need assistance completing the simplified application, as it is still too complicated for them to complete alone. MinnesotaCare also requires a premium, which is either financially prohibitive or objectionable on Federal Trust Responsibility grounds, for some AI/ANs. AI/AN elders, in particular, object to being required to pay a premium or actively apply for government programs due to the Federal Trust Responsibility to provide health care to AI/ANs.

The State of Minnesota has undertaken a variety of activities to increase enrollment in the public insurance programs, but statewide interviewees said there is always room for improvement in ensuring that all eligible AI/ANs in the State are enrolled. Their suggestions to increase enrollment include targeted funding for Tribal advocacy positions to provide one-on-one assistance and case management, easier application process for Tribes wanting to administer their own MA program, more transportation assistance, additional program training at the local level for Tribal professionals, and greater provider and consumer education about the benefits of the programs. Some even suggested that the Federal Trust Responsibility to provide health care be fully extended to urban AI/AN populations

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

According to Minnesota's DHS and Indian Elder Desk, there is serious AI/AN underenrollment in the MA program Statewide. They believe, however, that most AI/AN families and children eligible for MinnesotaCare are enrolled. They also think that most AI/ANs in Minnesota are aware of the two programs but do not have detailed knowledge of them, although DHS stated that substantial program information is provided to both Reservation and urban-based AI/ANs. DHS interviewees also noted that many Minnesota Tribes have satellite health clinics and/or offices in urban areas which are valuable for helping to raise program awareness and enrollment.

#### **Barriers to Initial Enrollment**

State-level agencies and organizations reported the following barriers to initial enrollment in MA and MinnesotaCare:

- AI/ANs in Minnesota (except for Mille Lacs Band members) particularly those who live on Reservations are unwilling to apply at County human services offices. Main reasons include lack of reliable transportation modes, substantial transportation distances, and significant office waiting times. DHS felt this was not as much of an issue with urban Indians. Although application for MA and MinnesotaCare can be accomplished through the mail (and over the telephone in a few pilot areas), DHS thought that many AI/ANs in the State think they still need a face-to-face interview at County offices.
- Even with mail-in application and a recently simplified application form, many AI/ANs still need assistance completing forms and providing required documentation. One of the

primary reasons is language and cultural barriers. According to interviewees, AI/ANs may not understand the language used in the application documents (either because of literacy issues or terminology used in the forms) and the government may not understand AI/AN cultural nuances when interacting with AI/ANs. For example, County workers may misinterpret an AI/AN's inability to provide a birth certificate as reticence on the individual's part to comply with the application's documentation requirements.

- There is substantial mistrust among AI/ANs of government programs, according to the non-DHS Statewide interviewees.
- A significant number of AI/AN grandparents are raising their grandchildren and may need short-term daycare assistance to travel to County human services offices (not realizing they can mail in the application if they can complete it without assistance).
- MinnesotaCare charges an enrollee premium except for AI/AN-enrolled children. Because many AI/ANs view the provision of health care as a Federal Trust Responsibility, they do not feel they should have to pay premiums and some will not enroll.

#### Barriers to Maintaining Enrollment

MinnesotaCare requires annual, and MA requires bi-annual, redetermination. Minnesota has attempted to streamline the redetermination process over the past several years. Redetermination forms are mailed directly to an enrollee's home from one central location or can be downloaded from the Internet. The form is now a single page, is provided in 10 languages (as is the initial application form), and does not require a face-to-face interview. The only redetermination barrier cited by statewide interviewees concerned loss of MinnesotaCare by some AI/ANs due to their failure to pay premiums. For instance, according to DHS interviewees, the most frequent reason that people in general (not just AI/ANs) lose MinnesotaCare coverage is failure to pay the premium.

# Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Interviewees universally said that most AI/ANs in Minnesota are aware of Medicare but lack detailed knowledge about the program. For example, elders often do not understand the difference between the Medicare and MA programs or between Medicare Parts A and B. Additionally, DHS interviewees think there is serious under-enrollment in the Medicare Savings Programs among AI/ANs statewide. They said that under-enrollment in the Medicare Savings Programs is caused mainly by the same factors previously described that lead to under-enrollment in the MA program, with the following additional limitations:

• DHS interviewees believe that elder AI/ANs are perhaps even more likely than younger AI/AN populations to resist enrolling in government-sponsored health care programs due to belief that there is a Federal Trust Responsibility to provide health care to AI/ANs in exchange for the land their ancestors ceded to the Federal government. DHS interviewees noted that AI/AN elders often do not understand why they do not currently receive a

more comprehensive range of health care services (e.g., long-term and preventive care) through IHS or other AI/AN-targeted programs.

- Elder AI/ANs for the most part have never had to pay health insurance premiums before age 65 and do not understand why they must start paying Part B premiums when they turn 65, particularly when their incomes are likely to be more limited.
- Income from work provided under the Older Americans Act (the Senior Service Community Employment Program) is counted as cash income for the Medicare Savings Programs, but not for food stamps and many other social welfare programs. Interviewees said this is not only confusing to many elders, but makes them ineligible for the Medicare Savings Programs. Social welfare programs also have varying eligibility age requirements, which is also confusing to elders.

# Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

Interviews with Statewide agencies, particularly with DHS and Indian Elder Desk staff, indicated that the State of Minnesota appears to be very active in ensuring that all AI/ANs in the State are aware of, and enrolled if eligible, in the three public insurance programs. Following are the current activities the State undertakes to promote enrollment:<sup>161</sup>

- Outreach by Minnesota Board of Aging Staff. Almost continual travel by the Minnesota's Board of Aging Indian Elders Desk staff to Tribal communities builds trust and relationships and to provide IHS and Tribal patient benefit coordinators with materials and training. Indian Elders Desk staff also works through Wisdom Steps to educate and assist AI/AN elders.
- Medicare and MA program training for Minnesota State Health Insurance Assistance Program (SHIP) staff and volunteers. Indian Elders Desk hold regularly-scheduled Medicare and MA program training for Minnesota State Health Insurance Assistance Program (SHIP) staff and volunteers, using Wisdom Step training materials specifically developed by and for AI/AN elders. Indian Elders Desk staff also continues to work through the State's Senior Linkage program to raise program awareness.
- Coordinated and Integrated AI/AN Outreach Effort. The State is planning for a coordinated and integrated AI/AN outreach effort among all related State agencies for one month this year.
- DHS and other associated State agency quarterly meetings with Tribal health directors to inform them about State health insurance program changes. The State relies on the Tribal health directors to relay the information to their Tribes (but did not elaborate about the specific mechanisms health directors use to distribute information to Tribal members or on how effective this is). The State is also in the process of establishing regular meetings with the Metropolitan Urban Indian Directors organization, which consists of directors from all (not only health) urban AI/AN organizations in the State.

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<sup>&</sup>lt;sup>161</sup> The site visit team did not collect information on length of time the activities have been occurring or whether the State or others have reported or published measurable results for the activities.

- Exemption of Tribal member enrollment in MA or MinnesotaCare managed care plans (except for Mille Lacs Band members). The State does not require Tribal enrollment until a Tribe has funding for outreach and enrollment assistance. DHS is trying to obtain State funding for these activities for additional Tribes.
- Program Training. The provision of program training to Tribal clinics or other Tribal staff upon request if the State has available resources would help to increase enrollment.
- State participation in several grant-funded outreach programs, although none are focused exclusively on AI/ANs: 162
- The State has a Robert Wood Johnson Foundation (RWJF) grant, "Supporting Families," that funds State initiatives to reduce administrative barriers to Medicaid and SCHIP enrollment.
- For the sixth year, the State has provided \$750,000 for the MinnesotaCare Health Care Programs Outreach Grant Project for community-based organizations. Although the grants initially targeted outreach for MinnesotaCare, they have expanded to include MA outreach because families may have members eligible for both programs. The grantees initially relied on general outreach and education approaches, such as television, radio, and newspaper advertising, but through experience have narrowed down outreach activities to one-on-one efforts because they feel these work best. The Red Lake Band of Chippewa and the Lake Superior Band of Chippewa currently have outreach grants. 163
- The State Solutions Grant, funded through The Commonwealth Fund and RWJF, is designed to increase enrollment of Medicare/Medicaid dually-eligible persons. Last year, the State also received a CMS-sponsored grant for the same purposes.
- The State supports Minnesota's "Covering Kids" grant by working with the State's grantee administrator, The Children's Defense Fund. In particular, State staff participates in the Statewide steering committee for the grant, and is currently working with The Children's Defense Fund to place an eligibility worker in one of Minneapolis' new Family Centers.

Statewide interviewees said there is always room for improvement in ensuring that all eligible AI/ANs are enrolled in public insurance programs. Following are a number of the specific strategies they suggested could be implemented to facilitate enrollment:

• Targeted funding for Tribal advocacy positions to provide one-on-one assistance and case management when needed. The director of the Indian Elder Desk believes that this is the most, and perhaps only, effective way to increase AI/AN program enrollment. Tribal advocates must be people who are trusted in their community. She suggested that Tribal advocacy funds should be appropriated specifically for this reason.

<sup>&</sup>lt;sup>162</sup> The site visit team did not collection information from the State about the effectiveness of the outreach programs or whether data are available to assess effectiveness, as these issues were outside of the project's scope of work.

<sup>163</sup> http://www.dhs.State.mn.us/HealthCare/pdf/grant-fact-sheet-8-6-02.pdf, accessed on January 25, 2003.

- CMS should make it easier for Tribes to administer their own MA programs. The State waiver application to allow the Mille Lacs Band to administer its own MA program took a very long time to negotiate with CMS. State respondents believe that the Mille Lacs Band's experience has been very successful in increasing Band member enrollment, and other Minnesota Tribes would probably have the same experience if they were to do likewise. However, the respondents noted several reasons why other Minnesota Tribes have not applied for MA self-administration: lack of infrastructure (e.g., for coding, billing, auditing, and follow-up systems), lack of development funds, and lack of administrative resources. Mille Lacs has a very sophisticated health care system and was also able to use its gaming money to address these issues. Additionally, Tribes outside of Minnesota may not have AI/AN representation in their State's government (e.g., Minnesota DHS has had an AI/AN Native American liaison and an AI/AN at the Indian Elders Desk since 1994) to support Tribes with the waiver process. Respondents recommended increased funding for Tribes to address infrastructure, development, and administration issues.
- **Transportation Assistance.** All interviewees agreed that greater transportation assistance for AI/ANs is needed.
- Program Training at the Local Level. According to Indian Elder Desk staff and EpiCenter interviewees, Tribal professionals, including those who work at Elder Nutrition Centers and Elder Advocates, need program training at the local level. There should also be provider and consumer education about the benefits of the programs, including increased awareness that greater enrollment in MA, MinnesotaCare, and Medicare and the Medicare Savings Programs frees up Tribal funds for additional services. IHS and CMS should increase their respective commitments to work with Tribes to provide information and education to them regarding the availability and benefits of these programs. The information should emphasize that the programs are an extension of the Federal Trust Responsibility to AI/ANs.
- Include Urban AI/AN Population in Federal Trust Responsibility. Several interviewees suggested that the Federal Trust Responsibility should be fully extended to urban AI/AN populations. 164 Urban areas have large pockets of program underenrollment.

#### Other Issues

According to DHS staff interviewed, the State of Minnesota is currently facing a budget deficit that prohibits it from addressing many of the issues that affect AI/AN program underenrollment. Also, States are confused about the IHS/CMS Memorandum of Understanding, stating that inconsistent policies are applied across States.

<sup>&</sup>lt;sup>164</sup> According to one of our project's consultants, the Federal Trust Responsibility already applies to individual AI/ANs, rather than to tribes or Reservations. The shortfall is in funding for urban Indian health programs, not in the scope of the legislation's provision for who is eligible.

#### FINDINGS: FOND DU LAC RESERVATION

# Overview

During our site visit to Fond du Lac, we interviewed the Director and Associate Director of Tribal health services, as well as staff from the Min-No-Aya-Win Clinic, the Title VI Senior Services Director, the Tribal Executive Director, and the Tribal Community Services Administrator. Subsequent to our site visit, we also interviewed by telephone the Medical Social Workers from the Min-No-Aya-Win Clinic on the Fond du Lac Reservation and the Center for AI/AN Resources in Duluth.

The Fond du Lac Band of Ojibwe funds many of its new community programs, housing, and community facilities from casino revenues and income from other Tribally owned enterprises. These revenues have assisted the Tribally operated health clinics to markedly increase third-party billing through investments in sophisticated accounting and billing systems and staff. The Tribe also pays Medicare Part B premiums for those eligible for Medicare but ineligible for the Medicare Savings Programs. These strategies have been coupled with a very strong and continual emphasis in the Tribally operated health clinics on provider, staff, and client education about the individual and community benefits and importance of third-party revenues, as well as consistent leadership to sustain these education efforts over the past several years. These strategies have markedly increased enrollment in MA and Medicare, and associated revenues, according to those interviewed.

It was a general consensus of those interviewed that under-enrollment in MA is a bigger problem than in Medicare on the Fond du Lac Reservation and is a somewhat serious problem. Enrollment barriers cited include resistance to divulging personal information at County human services offices and a general distrust of government programs. This includes fear that application information will be shared with the State's child support enforcement agency. Interviewees also said enrollment barriers include a general reluctance to fill out paperwork for government programs that should be automatic through treaty rights, a highly transient population, lack of transportation and telephones, low literacy skills, and lack of awareness of programs and/or program benefits. Another barrier concerns the ability of a health facility to successfully bill third-party insurance with lack of ability lowering the facility's incentive to screen and enroll patients in third-party insurance programs.

Interviewees said that Band members who do not access medical services tend to be the largest group of under-enrolled in MA. Interviewees said there is little Tribal or State-assisted outreach, program benefits education, or one-on-one application assistance for non-Tribal clinic clients. In addition, there is limited training and use of other Tribal members who might be able to provide this education and application assistance to non-clinic clients. The clinic's strategies to date have focused on reaching and educating people who visit health facilities.

Health facility staff said they generally do not discuss MinnesotaCare with clinic patients, as most are not eligible for the program.

Tribal health facility staff stated that the only way to maximize enrollment in MA, MinnesotaCare, and Medicare among Tribal members is to ensure that the "whole system" works

together, and there is consistency of awareness and purpose from Tribal leadership on down. Along these lines, those interviewed recommended increased funding for hiring Tribal employees to assist with program application, Tribal staff training and consumer education, program and systems development, and investments in third-party billing technologies. They also suggested that exempting Medicare and MA certification for Tribally-operated health facilities would allow more Tribes to be able to bill third-parties, increasing their incentives to screen for third-party insurance and provide program application assistance.

According to several interviewees, most AI/ANs who live on Reservations have incomes too low to qualify for MinnesotaCare, or have private employer-sponsored insurance, so health facility staff generally does not discuss this program with clients.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

It was a general consensus of those interviewed that under-enrollment in MA on the Fond du Lac Reservation is a somewhat serious problem. Min-No-Aya-Win Clinic staff workers estimated that about 25 percent of the Reservation population is enrolled in MA, and about 12 percent are eligible but not enrolled. AI/ANs who do not visit health facilities on a regular basis or at all are the most likely to not be enrolled in MA. Interviewees agreed that the Tribally operated clinics do a pretty thorough job of screening for third-party eligibility and providing enrollment assistance.

#### **Barriers to Initial Enrollment**

Interviewees most frequently reported the following barriers to initial enrollment in MA:

- Health care is a treaty right and a Federal government responsibility. AI/ANs, therefore, should not have to divulge personal information to others, particularly at a County human services office. Additionally, many AI/ANs have a general distrust of government programs. Although applicants in Minnesota do not need to apply or re-certify for MA at a County human services office, several interviewees said that many AI/ANs do not realize this.
- A highly transient AI/AN population, especially among economically disadvantaged persons, is another issue that makes it difficult for people to enroll and stay enrolled in MA due to movement to other States and lack of a permanent address.
- There is a welfare stigma associated with having MA coverage.
- Illiteracy is a big problem for Fond du Lac AI/ANs, causing difficulty in completing applications and understanding the benefits of the programs.
- Some lack access to a telephone that would enable them to obtain assistance from the clinic or the County human services office in completing applications.
- Some Tribal members have a perception that MA providers are insensitive to AI/AN
  health care needs or ways of having those needs met, causing disincentives to enroll in
  MA.

- There is fear that MA application information will be shared with the State's child support enforcement agency, which will cause the absent parent to be contacted for child support if in arrears.
- Tribal clinic staff felt that billing issues could represent a substantial barrier to enrollment because many clinics outside of Fond du Lac will have no incentive to encourage patients to enroll in Medicare, MA, or MinnesotaCare if they are not able to bill for these services. The two Tribal clinics in Fond du Lac, therefore, placed a high priority on building a well-functioning electronic billing system, which they stated has led to a large increase in third-party revenues. Clinic staff felt, however, that some Tribal clinics outside of Fond du Lac are reluctant to change their current billing system for fear of doing something wrong and inviting trouble from the government for fraud, or would feel ashamed if they made a mistake. They said many clinics' budget systems are based on IHS grants and would need a lot of work to transform them into a sophisticated encounter-based billing and accounting system.
- Another billing issue that arises, even when AI/ANs are enrolled in MA or Medicare, is that some beneficiaries balk at having to provide their MA/Medicare number to the clinic. According to interviewees, some patients feel that the Indian clinic is "their" clinic and they should not have to do this.

### Barriers to Maintaining Enrollment

- Redetermination for MA is every six months, requiring recipients to go through the
  application process too frequently, according to those interviewed. The redetermination
  process itself is not very complicated but MA program communications with consumers
  are often difficult for them to understand. For example, a denial or acceptance letter may
  be five or six pages long.
- Some Tribal members do not understand the value of MA benefits if they have not needed to access them much in the past, and feel that the "cost" of filling out the redetermination forms outweighs the program's potential benefits.
- Fluctuating income causes some AI/AN recipients to cycle on and off MA.

#### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Medicare Part B under-enrollment for the past three years is a very small problem for Fond du Lac Tribal members living on the Reservation. This is because the Tribe has used revenues from its casino and other Tribal businesses to pay the Medicare Part B premium for all eligible elder Tribal members, irrespective of income and place of residence, if the Tribal member is not eligible for the Medicare Savings Programs. The lack of Part B enrollment, if any, is usually discovered at a Tribal clinic when the patient comes in for a particular service.

The most frequently stated reasons for under-enrollment in Medicare Part B include:

- AI/AN elders in general are not aware of the benefits of Part B coverage, and therefore do not understand why they should enroll in Part B. Many elders have very limited incomes and do not want to pay the Part B monthly premium, feeling that it is too costly for the perceived benefits.
- According to those interviewed, the mentality in much of Indian County is that health services will be, and should be, covered by the Federal government. Therefore, AI/ANs should not have to pay the Part B premium to access Part B benefits.
- AI/ANs are generally unaware of the availability of the Medicare Savings Programs.

# Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

Tribal health facility staff stated that the only way to maximize enrollment in MA, MinnesotaCare, and Medicare among Tribal members is to ensure that the "whole system" works together and that there is consistency of awareness and purpose from Tribal leadership on down. Interviewees noted, however, that it is not possible to design a single systematic approach that will work best for each Tribe or community. They believe that the best way to develop one is to find the cultural norms in each community that are consistent with good stewardship of resources, develop a rationale for this stewardship, then integrate the rationale into the existing "business" process. They suggested, however, that the following components are important to any systematic approach to increasing enrollment and third-party revenues:

- A sophisticated billing office staff and good billing, accounting, and medical information computerized systems. Billing is still done by hand in many Tribally operated facilities outside of Fond du Lac according to the interviewees.
- Funding that allows Tribal employees (of health clinics, social services programs, senior centers, etc.) to work directly with Tribal members to assist them with enrollment and reenrollment. One-on-one assistance is crucial in many cases to successfully enroll Tribal members. Clinic staff and other Tribal employees are in the best position to ensure that Tribal members become enrolled.
- Accurate and frequent training for Tribal employees and easy access to program information. At present, Tribal employees who provide application or redetermination assistance need to make numerous phone calls to find someone who has detailed knowledge about the specific program with which they need help. The medical social workers at the Tribal clinics said they have good contacts at their County human services offices although County workers can be difficult to reach. Clinic staff also sometimes rely on the Lake Superior Health Access staff for information and client enrollment assistance (see description below).
- Aggressive screening and incentive systems in health facilities.
- For example, the two Fond du Lac clinics recently began requiring patients to provide their MA, MinnesotaCare, or Medicare card or number (or proof of private insurance) at

registration to obtain services. At each point of their visit, clinic staff has agreed not to provide services if this has not been done. If a patient cannot show proof of third-party insurance or has not been screened for third-party eligibility in the past, the patient is referred to one of the clinic's medical social workers for screening. The clinics also require proof of MA/Medicare application before the patient can receive Contract Health Services. Clinic leadership said that they spent considerable time educating staff – from physicians on down – and the community on the importance of patients providing this information so the clinic can get more funds to provide better health services. Since they started requiring proof of application, some AI/ANs with large medical expenses have not been able to have their expenses paid, which has "provided a lesson to other community members about the importance of third-party enrollment."

- The medical social workers at the two Tribally operated clinics are "aggressive" about screening patients for MA, Medicare, and Medicare Savings Programs eligibility. The clinics recently designed a screening questionnaire, based on their own acquired knowledge, to screen clinic patients for all third-party insurance programs. This reduces wasted time and negative word-of-mouth from persons who might complete applications but are not likely to be eligible for a program. All clinic patients, if needed, are screened for eligible programs at registration and are sent to the medical social workers if they cannot provide proof of application to these programs.
- The medical social workers help people complete the paperwork for initial application or redetermination for MA or Medicare, try to educate people about the benefits of all third-party insurance programs, send reminders to home addresses that redetermination for MA is required if designated as a representative on the MA application, <sup>165</sup> conduct home visits to help with the application or redetermination process if someone requests assistance, and will even accompany the person to the County human services office if needed.
- Effective consumer education to raise awareness of the availability of third-party insurance programs and their benefits, with benefit education encompassing both individual and Tribal/community benefits. Clinic staff feels it is vitally important to stress the community-sharing aspects of program enrollment to help AI/ANs understand why they should enroll in the programs. Clinic staff employs messages such as "If you don't sign up for these programs, you are squandering Tribal resources," or "Program enrollment ensures that the administrators of the Tribe's health care are being good stewards of the Tribe's money and are not treating some members better than others." Another message that seems to be effective is "Every other hospital gets to bill for MA and Medicare-covered services, why shouldn't we?"
- Consumer education is best done during Tribal meetings, held for any purpose (e.g., foot clinics for diabetics). Brochures, posters, etc., are not generally effective communication

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<sup>&</sup>lt;sup>165</sup> The medical social workers at the two Tribally-operated clinics said they usually only encourage frail elderly to designate the social workers as representatives on the MA application so the social workers will also receive redetermination notices. Social workers said they will serve as representatives for others if requested. They said, however, that although some frail elderly will list them as representatives, many are too proud to do so. They also said they try to maintain a manual tickler file to help remind patients when their redetermination forms are due.

methods. Instead, information has to be integrated into the Tribe's existing system. The most effective form of communication with AI/ANs is through face-to-face discussions, which can be accomplished by partnering education activities with other Tribal activities. In addition, consumer education needs to be frequent and on going. Aspects of the MA and Medicare programs often change and consumers need to be informed of these changes on a frequent basis. However, it is most important that Tribal staff understand the changes so they can explain them to patients.

• A Tribal leader who continually focuses on a systematic approach, Tribal staff training, and consumer education. As well, the approach requires continuity of staff and leadership.

Besides taking a community-based systematic approach to ensuring maximum program enrollment, Fond du Lac relies on several other strategies.

- Use Revenues from Casino to Pay the Medicare Part B premium for Tribal Members. Fond du Lac is relatively unique in that for the past three years, the Tribe has used revenues from its casino and other Tribal businesses to pay the Medicare Part B premium for all eligible elder Tribal members, irrespective of income and place of residence, if the person is not eligible for the Medicare Savings Programs (about 25 percent of elders are enrolled). The Tribe decided it would save money in the long run by ensuring that all Medicare-eligible Tribal members were enrolled in Part B. If a person is not eligible for the Medicare Savings Programs, the person receives a check four times a year equal to the amount of the Part B premiums paid. The Tribe does not yet have data to show that its strategy is effective, but it believes the data eventually will indicate this.
- Training for Home Health Nursing Aides. The medical social workers at the Tribally operated clinics have recently begun to train home health nursing aides (funded through Federally-Qualified Health Center funds) to assist their patients with the application and redetermination processes for Medicare and MA and to explain the benefits of the programs. Many AI/AN elderly at Fond du Lac use home health nursing aides. Currently, CHRs will assist with outreach in the community when their time allows (which is not often).
- State Grants. The State has provided several grants to Tribes to do more aggressive outreach and enrollment assistance for MA and MinnesotaCare (described previously). The medical social workers at the clinics are aware of such a program in St. Louis County and sometimes refer non-enrolled patients to them.
- **Wisdom Steps.** Interviewees unanimously lauded the Wisdom Steps program (described previously), in which the State uses it regularly scheduled conferences to provide education about Medicare and the Medicare Savings Programs to elders and other attendees. The medical social workers at the two Tribal clinics find these sessions very helpful for elders and themselves.

• Indian Legal Aid, for which eligibility is income-determined, is available to help AI/ANs with program denials or other legal issues. Public health nurses and Community Health Representatives provide very limited medical transportation.

Interviewees discussed additional ways that CMS, IHS, or the State can help them, and particularly other Tribally-operated clinics with less Tribal revenue assistance, to improve AI/AN program enrollment:

- **Increased Funding**. Increased funding would allow more Tribal employees (of health clinics, social services programs, senior centers, etc.) to work directly with Tribal members to assist with enrollment and re-enrollment processes.
- **Program Training for Tribal Staff.** More program training for Tribal staff that explains all three programs, as well as program interaction with other public benefits programs, is necessary to increase enrollment.
- **Support for Program and Systems Development.** Increased support for program and systems development would increase Tribal and clinic staff support of the education, screening, application assistance, and third-party billing processes, thereby providing greater incentive for program enrollment.
- Improved Communications. Interviewees noted that improved communications through additional funds directed to Tribes would be helpful so that Tribes can hire Tribally-based staff to conduct increased home visits, provide direct mail to homes, place articles in local Tribal papers, and conduct awareness campaigns on the Reservation's web page targeted at AI/ANs who do not come to the Tribal clinics. Additionally, interviewees suggested that the Senior Linkage Line that provides classes for elders regarding prescription drugs could be expanded to include MA, Medicare, and Medicare Savings Programs education.
- **Transportation**. Increasing funding for transportation assistance for medical appointments and program application.
- Computer Access and Education. Computer access and education to allow Tribal members to enroll in insurance programs on-line. While there is currently a resource library at the Tribe's Elder Center, most staff and elders do not know how to use the computer.
- Additional Funds to Improve Billing and Accounting Systems. Provide additional funds to IHS contracting/compacting Tribes to help make their billing and accounting systems compatible with IHS' Resource and Patient Management System (RPMS), and to help ensure that Tribes can effectively bill third parties through investments in the appropriate technologies, including those for medical information systems. These initial investments are likely to be paid for over the longer term through increased third-party revenues. Until this is done, health clinic staff recommended that the IHS/Tribal/Urban (I/T/U) system be exempted from Medicare and MA systems, which require sophisticated billing systems.

• Exemptions to Medicare and MA Certification. Health clinic staff also suggested exemptions to Medicare and MA certification be granted for Tribally operated health facilities. They believe many facilities cannot meet these requirements and cannot bill for covered services.

## Other Issues

Additional issues not directly related to enrollment in the MA, Medicare, and MinnesotaCare programs surfaced during our discussions with Tribal health staff:

There are 547 distinct, sovereign governments comprised of Tribal governments across the United States. According to those interviewed, all Federal agencies should understand this in working with Tribes. <sup>166</sup> Interviewees also noted that CMS needs to appreciate that it is a "partner in the Federal obligation" to pay for health care for Federally Recognized Tribes. One way the agency can help do this is by simplifying the billing system between the I/T/U system and the Medicare and Medicaid programs.

The Federal Trust Responsibility is a special condition for the AI/AN population compared with all other minority or special populations. One way to signal this recognition, as recommended by the health clinic staff interviewed, is through higher visibility of CMS's "Indian Desk" activities at its headquarter offices in Baltimore (i.e., the Intergovernmental Tribal Affairs Office) and through CMS's National Tribal Technical Advisory Group (TTAG) activities

CMS should not leave CMS policy interpretation to its Regional Offices due to inconsistent interpretation by region. This is confusing to Tribes, as well as sometimes divides Tribes and pits them against each other in their attempts to increase their share of funding.

CMS could examine and honor "bests State practices" with Tribes. The agency could, for example, highlight how a State effectively addressed some health disparities.

#### FINDINGS: MILLE LACS RESERVATION

# O<u>verview</u>

During our site visit to Mille Lacs Reservation, we discussed program enrollment barriers and solicited strategies to increase enrollment in MA, MinnesotaCare, and Medicare with Mille Lacs' Tribal health director, the Title VI senior services director, the director of Tribal community support services, staff from Contract Health Services, patient benefit coordinators at the Ne-Ia-Shing Health Clinic, and five elders residing at the Mille Lacs AI/AN Assisted Living

<sup>&</sup>lt;sup>166</sup> For example, health clinic staff interviewees said that Minnesota's MA program did not consult with tribes when it submitted its first 1115 Medicaid waiver to CMS. The tribes complained to CMS about this and CMS rejected the waiver. The State now consults tribes before waiver submissions.

Center. Following the site visit, we also conducted telephone interviews with the Circle of Health director and a medical social worker and elder advocate from Mille Lacs. <sup>167</sup>

The consensus of those interviewed was that under-enrollment (or redetermination) in Medicare, MA, and MinnesotaCare does not appear to be a problem for the Mille Lacs Band of Ojibwe members. The primary reason stated is the substantial revenues the Band receives from gaming, which has allowed them to expand health services, employ more clinic and outreach staff to provide screening, application assistance, and establish redetermination systems, and to initiate the Circle of Health program that pays for Band members' health insurance premiums (including Medicare Part B premiums), co-payments, and deductibles. Also of substantial importance according to those interviewed, since 1999, the Mille Lacs Tribal government has administered its own TANF, Food Stamp, and MA programs for Band members. According to Tribal interviewees, this has significantly increased MA and Medicare Savings Programs enrollment and billings. It was pointed out repeatedly by Tribal and State interviewees, however, that gaming revenues – in combination with Tribal willingness and participation – enable Tribal self-administration of these programs. Gaming revenues have allowed the Tribe to build the infrastructure needed (e.g., for coding, billing, auditing, and follow-up systems) and provided development and administration resources, to which many Tribes outside of Mille Lacs do not have access.

Despite the above advantages, some Mille Lacs Band members living on the Reservation still face barriers to accessing health programs and health services, according to interviewees. The primary barriers noted are lack of reliable transportation and a lack of understanding of why Band members should enroll in third-party insurance programs when they have, and should have, access to Tribal facilities and the Circle of Health program.

As with Fond du Lac, Mille Lacs Band interviewees reported that few members are eligible for MinnesotaCare, due to either insufficient incomes (making them MA eligible) or because they have employer-sponsored insurance.

Mille Lacs Band interviewees said there are few problems with Medicare eligibility for Band members. Most elderly members have Medicare Part A due to work eligibility. Of the 275 to 300 elders living on the Reservation, almost all are enrolled in Medicare Parts A and B and the Medicare Savings Programs, if eligible. Most are not eligible for the QMB or SLMB programs because their income is too high (the interviewees had not heard of the QI-1 or QI-2 programs). Band members receive bonuses from Tribal profits related to their casinos and other enterprises, which can make them ineligible.

Band members can obtain MinnesotaCare applications and application assistance from the Tribally operated MA program (as well as from the Tribal health clinics and other Tribal offices) but most Band members are not eligible for MinnesotaCare. Band members seem to either have low incomes that make them eligible for MA, or are working and have employer-sponsored health coverage. Many Band members are employed at the Tribally owned casinos.

<sup>&</sup>lt;sup>167</sup> We also tried to schedule a follow-up telephone interview with the Benefits Issuance Director for the Tribal TANF program, based on recommendations from Mille Lacs interviewees, but were not able to contact her to schedule a time.

Tribal clinic staff said they had not invested much time in understanding program requirements for MinnesotaCare, and there was general lack of Tribal familiarity of the program among all interviewed.

# Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

It was the general consensus among those interviewed that under-enrollment of the Mille Lacs Reservation population in MA and MinnesotaCare is low and that consumer awareness of the MA program is high. Interviewees agreed that the Tribally operated health clinic does a fairly thorough job of screening for third-party eligibility and providing enrollment assistance. As important as clinic screening for increasing program enrollment, Mille Lacs is unique in that it runs its own TANF and MA programs (described in further detail below).

#### Barriers to Initial Enrollment

The most frequently reported barriers to initial enrollment in MA include:

- The lack of reliable transportation, particularly for handicapped, younger adults. This is the largest barrier, which the Tribe has not addressed. (Many Tribal members do not have a driver's license.) Although mail-in application is possible, Tribal staff interviewed did not mention it as a possibility for overcoming transportation barriers.
- The Tribal leadership and Tribal health staff experience communication difficulties with Tribal members who move frequently and/or who move without providing a new address. The Tribe's enrollment office does pro-actively try to track down a new address.
- A few Band members are reluctant to apply for any State or Federal government program due to mistrust or privacy issues. Many do not want to deal with any non-Reservation government agencies.
- A few Band members do not want to make the effort to enroll in MA because they have easy and free access to Tribal health services.
- There is a welfare stigma of being on MA.
- Some Band members, particular the elderly, lack access to or are uncomfortable with several technologies for pursuing information or communications, including answering machines, "voice trees," and the Internet.
- Application difficulties sometimes arise from illiteracy, being asked the same question over and over, privacy issues, and lack of ability to provide all documentation required (such as birth certificates and bank Statements).

# Barriers to Maintaining Enrollment

Redetermination for MA and MinnesotaCare is not much of a problem according to those
interviewed. The Tribally operated health clinic in each Mille Lacs Reservation district
has established a system for redetermination notices to be mailed directly to Tribal

offices. The claims processor at Circle of Health also helps track redeterminations for MinnesotaCare. Clinic staff reported that Minnesota's MA agency has been fairly cooperative and willing to send redetermination notices to authorized Tribal representatives.

• Redetermination problems, when present, occur most often among eligible younger adults who do not have as much access to application assistance as elders. Younger applicants also tend to move more often and more frequently need to deal with family crises that take precedence over the six-month redetermination procedure. Also, according to one respondent, "Indian people are not paperwork oriented."

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Those interviewed agreed that under-enrollment of Band members in Medicare and the Medicare Savings Programs is low and that consumer awareness of the programs is high. The most serious under-enrollment occurs in the more remote areas of the Reservation due to transportation problems and lack of access to current technologies, and for Band members who do not live on the Reservation – particularly those who do not live in the State.

High program enrollment is primarily due to a good system for health clinic screenings for third-party insurance eligibility, and the Circle of Health program. The Circle of Health director estimated that about 80 percent of eligible Tribal members are enrolled in Medicare Part B. Even if Medicare-eligible Tribal members do not want to apply for the Medicare Savings Programs, Circle of Health will pay their Medicare Part B premiums (although staff encourage and help them apply). Circle of Health may even pay part of the Medicare Part A premium for Band members without enough work experience to qualify for free. The Circle of Health program, however, causes some people not to enroll in Medicare Part B (and MA) because they think it is a primary insurance program.

Without Circle of Health, interviewees suggested that under-enrollment in Part B would be a much larger problem as many elderly Band members would not want to pay the Part B premium either due to financial reasons, because they do not understand the benefits of Part B coverage, or because they have access to the I/T/U system. Due to Tribal health clinic outreach efforts (described below), most elders have heard about Medicare and the Medicare Savings Programs, according to those interviewed.

The most frequently stated reasons for under-enrollment in Medicare Part B include:

- Lack of reliable transportation was reportedly the biggest problem Band members face in enrollment in Medicare Part B and MA. Some members live some distance from the center of their Reservation district making it difficult for them to visit a health clinic or attend community meetings. Lack of good transportation also makes it difficult for them to travel to a Social Security office to enroll in Social Security or Medicare if in-person enrollment is required due to a complicated situation or needed application assistance.
- A basic fear among some AI/AN elders of sending documents to a government agency, particularly if they have to reveal personal information such as income.

- A general lack of understanding by Band members as to why they should enroll in MA when they already have Medicare coverage.
- The perception among some interviewees that County human services offices sometimes think that Band members do not need MA or MinnesotaCare because they have Circle of Health coverage.

## Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

The Mille Lacs Band interviewees discussed several current activities and efforts that have helped them to successfully increase program enrollment among Band members. They were happy to share their strategies with others, which include:

- **Band administration of its own TANF and MA programs.** Before the Tribe began operating its MA program, interviewees said that Band members did not want to apply at the County human services offices because of perceived bias. The Tribe has detected a marked increase in MA enrollment since it began managing the program.
- "Circle of Health" coverage of premiums, co-payments, and deductibles for all Tribal members, irrespective of income or source of health insurance coverage (including employer-sponsored coverage). The program staff also assists Tribal members in applying for the insurance programs for which they are likely to be eligible.
- Tribally operated health clinic screening system for third-party insurance eligibility. The clinics also have computer systems connected to the State's MA enrollment database that allow clinic staff to verify enrollment or non-enrollment in MA (and MinnesotaCare). In addition, patients at all of the Tribally operated clinics are required to show proof of MA or other third-party coverage, or a proof of denial, to receive a Contract Health Services referral.
- Tribal maintenance of an office in Minneapolis for Band members, which includes a case manager who assists with program enrollment. Interviewees said the urban office has substantially helped to increase urban Band member enrollment in all three public insurance programs. According to interviewees, urban office staff has a pretty good relationship with the County human services office.
- Tribal sponsorship of a Band newsletter, direct mail-outs, and community meetings, all of which regularly provide information about the three programs. Community meetings include speakers invited by the Tribe's Senior Services and Community Services directors. The clinic staff felt that the newsletter is well received and is read, particularly as it is designed for and focuses on the community. Community and elder meetings are held in each Reservation district once a month. The Tribally-operated TANF program staff offer classes on Medicare and MA, visits people's homes to provide program information and application assistance, and is active in other ways to disseminate program information (e.g., attendance at health fairs). Interviewees felt that TANF outreach is very effective for Medicare and MA program enrollment.

- Elder Advocate Program. The Tribe is sponsoring a new Elder Advocate program, in which Tribal advocates will be trained to screen for MA, Medicare, and MA Savings Programs eligibility and provide application assistance. In additional to Elder Advocates, Band members can receive application assistance from the Tribal TANF program, any Tribal clinic benefits coordinator, Circle of Health staff, or Tribal social workers. Tribal social workers are also available in the Minneapolis/St. Paul area to assist with enrollment
- (MOA) signed by CMS and IHS in 1996. According to those interviewed, the Memorandum of Agreement (MOA) signed by CMS and IHS in 1996 (including the retroactive provisions of the MOA), has been a tremendous help in providing extra funds so the Band can create new staff positions including the hiring of the first social worker specifically for elders. The social worker assists elders with health and financial issues upon receiving referrals from CHS, nursing homes, County offices, and the Tribe's urban office.
- **Transportation.** CHRs and ElderCare aides are sometimes available to help with Band member transportation needs. However, their primary responsibilities are to provide home assistance.
- Legal assistance for program denials. Currently, there is limited legal assistance for program denials.

Although Mille Lacs Band interviewees feel they have been very successful in increasing program enrollment by effectively applying casino and other Tribal revenues to this goal, they provided the following additional recommendations to help achieve 100 percent enrollment among eligible Band members:

- Increased funding to hire two or more additional CHRs or ElderCare aides. These additional staff could provide transportation services to Band members who live in the Reservation's outer districts as well as in-person program application and assistance.
- **Transportation vehicles.** Funds to purchase a handicapped-accessible van and two full-time drivers to provide transportation services to Band members.
- Simplification of program eligibility criteria, program rules, and explanation of programs. (Examples of complex rules include: If a person misses applying for MA during an open enrollment period, he/she has to wait another six months to apply; Medicare beneficiaries do not understand why they have to pay a penalty on the Part B premium if they do not enroll shortly after initial eligibility). Interviewees noted that complicated rules and applications can cause AI/ANs to give up, especially after one bad experience.

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<sup>&</sup>lt;sup>168</sup> The MOA States that States can be provided 100 percent Federal MA percentage (FMAP) for payments made by the State for services rendered through an IHS owned or leased facility or a Tribal facility with funding authorized by Title I or III of the Indian Self-Determination and Education Assistance Act (Public Law 93-638, as amended). The MOA, signed December 19, 1996, notes that this FMAP is retroactive for services provided on or after July 11, 1996.

- Provide Band leadership with CMS- and SSA-produced materials about Medicare and the Medicare Savings Programs for Tribal use that specifically focus on benefits of the programs. Materials are best distributed through Tribal systems. Direct mail to households, even from Tribal offices, is not very effective. It is more effective to share these materials at community meetings, which are fairly well attended, and through the Tribe's outreach systems currently in place. One-on-one or small group education and assistance is most effective, which can be done at the health clinics or by Tribal human and social services staff.
- Separate application for TANF and MA. Use a separate application for TANF and MA to help reduce the welfare stigma of applying for and using MA. A different name for MA might also help reduce the stigma.
- Cross-training. Provide cross training for all public benefits programs, as well as annual update on programs. Currently, Tribal staff said they attend State training when offered, but for the most part need to invest their own time and efforts in understanding program details. Tribal staff often learns about available State training through the State's quarterly meetings (described previously).
- **Better Data.** The State, IHS, and CMS could provide data to the Tribe on program eligibility and enrollment at the individual level so the Tribe can better target their outreach resources.

#### Other Issues

Tribal interviewees discussed other issues not directly related to program enrollment that they felt were important to share with CMS, IHS, and others. First, the Tribal health director related that nationwide funding for CHRs was nearly lost recently because so many CHRs only have time to provide transportation assistance, which is a great need in their and other AI/AN communities. However, these services were not their intended goal.

Second, the Tribal health director said the Minnesota DHS and the Minnesota Board on Aging work well with the Tribes. They hold quarterly meetings that have good Tribal representation and CMS staff presence. The State has good and frequent communication with Minnesota Tribes, soliciting input into State health care planning. As an example of the relationship, the State first approached the Mille Lacs Band to be a pilot site for self-administration of the TANF/MA programs. The Tribes have achieved this level of communication by working with the DHS through Minnesota's Indian Health Board since 1990. The Board is now starting to hold discussions with the Minnesota Department of Health, which runs the State's public health programs, to improve communications and cooperation with Tribes. Mille Lacs Band, however, often has communication problems with County governments so members try to bypass the County level whenever they can. The two primary problems that AI/ANs face at local County offices are "unadulterated bias" and a general caseworker attitude that the County should not be spending "their" dollars on AI/ANs who already receive a lot of health care funding from casinos and the Federal government.

Finally, Tribal staff interviewed wanted to ensure that CMS recognizes that there are significant cultural differences, Tribal uniqueness, and a history of government relations that are important to understand when working with Tribes or on health programs that affect Tribal members. These also include Tribal sovereignty and Tribal-control issues. They emphasized that AI/AN Tribes are willing to work with all levels of government to help promote program enrollment among their members, but County, State, and Federal governments should work through Tribal governments to disseminate information.

#### FINDINGS: MINNEAPOLIS/ST. PAUL URBAN AREA AI/ANS

#### <u>Overview</u>

While in the Minneapolis/St. Paul urban area for our site visit, we interviewed in person the housing manager of the Elders Lodge in St. Paul. After our return, we held telephone interviews with the director and a licensed social worker from the MIHB, the administrator at the Hennepin County Medical Center, and the program manager for the Senior Linkage Line and Health Insurance Counseling, Metropolitan Area Agency on Aging.

According to all interviewed, under-enrollment in MA, MinnesotaCare, Medicare Part B, and the Medicare Savings Programs appears to be a much more serious problem in the Twin-Cities area than in the two relatively financially well-off Tribes we visited (Mille Lacs and Fond du Lac). Although the MIHB has enjoyed a national reputation for good third-party billings, there appear to be many urban area AI/ANs who do not visit the clinic and are not members of the Minnesota Tribes that have Twin Cities urban offices, and are therefore not enrolled in programs for which they may be eligible. This seems to be due to a general lack of outreach to AI/ANs in urban areas to inform them of the programs, educate them about the benefits of the programs, and provide application assistance. Additionally, training for professional people who might assist with education and applications, such as at non-Indian health facilities, elder residences, and senior centers, is lacking, according to those interviewed. Even at the MIHB, there is a need for additional staff to provide one-on-one application assistance. There are also significant transportation barriers in the urban area.

Recommendations from interviewees to increase program enrollment included increased training for all service providers and urban AI/AN Tribal offices staff on all public benefits programs available to low-income AI/ANs, offered on a consistent and frequent basis. They also recommended IHS/State funding for an on-site MA/MinnesotaCare eligibility worker at the MIHB, or at a minimum, a dedicated outreach position to help with program screening and application assistance, preferably of AI/AN descent, as well as funding for an urban area Indian advocate to help with application assistance and education. Interviewees also said that community education could be accomplished through funds for program advertising in AI/AN urban-area newspapers.

According to all interviewees, many elderly AI/ANs, similar to many elderly people in general, go without prescription medications if they do not have MA coverage, especially those whose income is a bit too high for them to qualify for MA. MIHB's social worker refers patients to drug company discount programs when she is aware of them. Some AI/ANs used to travel to Mille Lacs Reservation to acquire prescription drugs, if they could find transportation, since

Mille Lacs filled prescription medications for any AI/AN. However, in the last few years, Mille Lacs discontinued this practice as it became too costly, currently restricting coverage to Mille Lacs Band members.

MIHB interviewees noted that AI/ANs ages 62 to 65 are often the worst off in terms of health insurance coverage because they are not yet eligible for Social Security or Medicare but are not employed. (Those interviewed did not discuss whether these individuals might be eligible for Medicaid coverage and did not give a sense of the number of AI/ANs who might be a part of the 62 to 65 age group in this situation.)

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Under-enrollment in MA and MinnesotaCare is a somewhat serious problem in the Minneapolis/St. Paul urban area for those who visit the MIHB clinic or other area AI/AN centers, such as the Minneapolis American Indian Center. However, interviewees said it is a more serious problem for those who never visit the clinics or centers or do so on an irregular basis.

Respondents said they have never had any patients tell them that they were treated badly at the Hennepin County human services office, although the wait can be very long. Because of the barriers listed below, however, many people only apply for MA in a medical crisis or if they feel they may need substantial health care services during the year. Otherwise, urban AI/ANs know they can use the MIHB clinic or urban area hospital emergency rooms for much of their care.

#### Barriers to Initial Enrollment

The main reported barriers to initial enrollment in MA and MinnesotaCare were:

- Little formal or regularly scheduled State- or County-sponsored training for service providers (e.g., health facility staff and staff at elder group residences) who could assist AI/ANs with applications. Service providers often have to spend a substantial amount of time gathering the necessary information on their own, in a piece-meal fashion. Their information is often obtained through networking and/or identifying a particular contact in a State or County agency who will help them with details. As a result, often only one staff person has detailed knowledge of a single program that is lost when that individual finds other employment.
- Little knowledge among service providers of places where AI/ANs can regularly go for program application assistance.
- Lack of a permanent address for many urban AI/ANs, making it difficult for them to receive redetermination forms or for MIHB staff to keep track of their program enrollment status.
- Too much and too confusion application paperwork that requires considerable personal information (e.g., income and asset information, family member information, U.S. citizenship) that AI/ANs sometimes feel is meant to "catch them." (The Hennepin County

Medical Center uses the older 14-page form.) If a person does not follow through on just one section or piece of documentation, which happens frequently, the person will be denied coverage. There was a general feeling, particularly by the Hennepin County Medical Center interviewee, that the State is more concerned with "screening out" ineligibles than "screening in" eligible persons. Illiteracy in both English and their native language often exacerbates problems with completing applications.

- Although MA and MinnesotaCare application can be done through the mail (or by telephone in pilot counties), many AI/ANs need one-on-one assistance. If the application is too complicated, MIHB and Elders Lodge staff refers the patient to Hennepin County's human services office.
- Many AI/ANs do not follow through on application documentation because they cannot afford to acquire it (such as a birth certificate).
- Some AI/ANs live in multiple-family dwellings, but their name may not be on the lease. These individuals are reluctant to report this in a public program insurance application for fear of being evicted.
- Some AI/ANs get angry when they find out that the MIHB is not a fully funded IHS clinic and do not feel they should have to sign up for MA.
- Even for the few urban Indians who might be able to obtain services from facilities located on their Tribal Reservation, finding reliable and consistent transportation to the Reservation is often very difficult. Transportation within the urban area is also often a challenge. For instance, most of the residents of the Elders Lodge of St. Paul rely on Medicare, MA, Veterans Affairs, and private insurance to meet their health care needs as the MIHB clinic is too far away. It also operates on a sliding fee scale rather than being free, which some residents feel they cannot afford.

#### Barriers to Maintaining Enrollment

• Many AI/ANs are dropped from the programs because they do not follow up on redetermination (although respondents did not know why or how many are disenrolled).

• The Elders Lodge encourages residents to list a third-party for redetermination notice, either the Lodge or their family, but families are often not very responsive.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Most elderly patients who come to the MIHB and who live at the Elders Lodge are enrolled in Medicare Part A, but many are not enrolled in Part B. The main reported reasons for under-enrollment in Medicare Part B were:

<sup>&</sup>lt;sup>169</sup> It was beyond this project's scope of work to contact the State's certifying authority to obtain AI/AN redetermination data or to ascertain whether the State has analyzed AI/AN redetermination drop-out rates.

- Elderly patients feel that the Part B premium is too expensive and not worth its benefits (but they generally have little understanding of Part B benefits).
- Available literature to explain the programs is at too high a reading level and contains acronyms that lay people do not understand.
- "Indian people do not like to be asked personal questions," partially out of fear of government. However, at the MIHB and Elders Lodge, interviewees said AI/ANs are more open to answering such questions because they trust staff with whom they may have developed a relationship and/or AI/AN themselves. The MIHB social worker respondent said elderly patients particularly trust her because she is elderly herself.

# Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

Urban area interviewees related the following activities that either they pursue or are aware of for increasing AI/AN enrollment in Minnesota's public insurance programs:

- Formal screening process. MIHB has a formal system for screening clinic patients for MA, the Medicare Savings Programs, MinnesotaCare, and a special program available at the Hennepin County Medical Center. It includes patient registration upon admission to the central or any associated clinics; screening by a trained admission clerk; and referral to a licensed social worker at the clinic who can help with the application and required documentation. However, the social worker reported that only about one-half of patients referred to her become enrolled in a program for which they are eligible, mainly because she is only employed half-time and has additional duties. The social worker does not have enough time to help track redeterminations and follow-up on non-enrollments for all who need it, although she refers some people to the outreach worker at Hennepin County's Community Health Department for assistance. She is not aware of others in the urban area who can help with enrollment or of any County or State program or person dedicated to application assistance.
- Application assistance. Although not a part of her formal duties, the Housing Manager at the Elder Lodge in St. Paul assists residents with program screening and application when she has time to do so. The Elder Lodge recently hired a social worker, mainly funded through HUD, who is attending program training sessions sponsored by the State (primarily from Minnesota Board of Aging funds). She has developed her own screening and needs assessment form.
- Training on eligibility and enrollment issues. About four years ago, the State approached MIHB staff for training. Six staff members were trained, although only two of these staff still work at the clinic. The social worker tries to attend training updates when she learns of them and has the time. In addition, Minnesota's Board of Aging Indian Elder Desk staff has led Indian elder meetings once a month since 1999 where

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<sup>&</sup>lt;sup>170</sup> Hennepin County Medical Center has a similar system of screening for patients who present at the hospital, where potentially eligible but non-enrolled patients are sent to one of the hospital's Patient Benefit Coordinators for application assistance.

training is sometimes provided by State agencies. The State has also produced pamphlets on how to work with AI/ANs which have proven useful.

Although urban area interviewees are pursuing several strategies for improving program enrollment, their budgets appear to be stretched thin, particularly for hiring professional staff who can screen for program eligibility and then provide one-on-one program application assistance for the many AI/ANs who appear to need it. Their recommendations reflect their lack of funds as follows:

- Training and cross-training. Interviewees emphasized the need for increased training and cross-training, on a consistent and frequent basis, for all service providers and urban AI/AN Tribal offices staff on all Federal, State, and County public benefits programs available to low-income AI/ANs.
- Funding for an on-site MA/MinnesotaCare eligibility worker at the MIHB, or at a minimum, a dedicated outreach position to help with program screening and application assistance. MIHB interviewees said it collects a substantial amount of third-party revenues, but could collect much more with extra enrollment and redetermination tracking assistance. Ideally, they said the eligibility or outreach worker would be AI/AN as this is most effective for working with AI/AN populations due to greater respect and patience with clients. MIHB respondents said the Board has never requested an outstationed eligibility worker from the State or County.
- Dedicated funds for MIHB to advertise the programs in AI/AN newspapers in their urban area.
- Funding for an urban area Indian Advocate to conduct program outreach, education, and one-on-one application assistance. Although many of the Minnesota Tribes have offices in the Minneapolis/St. Paul urban area, their services are restricted to their Tribal members.

#### Other Issues

MIHB interviewees believe the clinic has a good relationship with the State because clinic staff has spent a substantial amount of time establishing good internal contacts between the clinic and State employees.

#### **DISCUSSION**

Minnesota's AI/AN population constitutes 1.1 percent of the State's entire population, comprising 34 Federally Recognized Tribes residing on 11 Reservations and in several urban areas of the State. Similar to the overall AI/AN population in the United States, more AI/ANs live in urban areas in Minnesota than on Reservations. Approximately one-third of Minnesota's AI/AN population lives in the central city areas of Minneapolis and St. Paul ("the Twin Cities"), with an additional 15 percent living in the Twin Cities suburbs.

As in many other areas of the country, poverty is prevalent throughout Minnesota's AI/AN population. On average, AI/ANs in Minnesota receive less than one-half of the income of

White households, with 44 percent living in poverty. This is due, in part, to the high level of unemployment among members of this population. Poverty is also more prevalent among the AI/AN population than other minorities in Minnesota, especially with regard to children. Additionally, AI/ANs in Minnesota experience significantly higher rates of disease and premature death than other population groups. Large disparities, for example, exist in rates of infant mortality, injury and violence, diabetes, and cardiovascular disease.

The Bemidji Area IHS office supports two IHS-operated short-stay hospitals, two health centers, and five health stations in three IHS Service Units. The Bemidji Area is unique, however, in that nearly all of the annual IHS funding allocation is distributed among the 34 Federally Recognized Tribes through self-governance contracts and compacts (97.4 percent as of FY 1998). The Minneapolis Indian Health Board is located in the Twin Cities area, which several of our TEP members and Project Consultants hailed as a model for other urban Indian clinics with respect to third-party billing procedures. However, because of recent staff changes during our site visit timeframe, we were unable to interview a larger number of staff to obtain more in-depth information about the clinic's Medicare and MA billing procedures and revenues.

The State of Minnesota appears to have invested in improving Tribal-State government relations through the funding and hiring of dedicated American Indian staff (e.g., Native American liaisons, the Board of Aging's Indian Elder Desk), establishing the Minnesota Indian Affairs Council, creating the Wisdom Steps program through the Minnesota Board on Aging, holding quarterly Tribal health directors meetings, working with Area Agencies on Aging, and participating in CMS-and foundation-funded outreach for MA and SCHIP programs. The Tribes we visited seem to have good relations with State health agencies, particularly the Indian Elders Desk staff. Both the State and Mille Lacs interviewees noted the successes of Mille Lacs Reservation in administering its own MA program for Band members, but they also all noted the relatively unique financial position of the Mille Lacs Tribe that has allowed it, in part, to accomplish this.

The State has also conducted several activities to help make it easier for all Minnesotans to apply for MA and MinnesotaCare, for example, by adopting a simplified four-to-six page application that can be mailed to a County human services office. According to the State's website, County staff will also help complete the application if needed. Additionally, the application is available in 10 languages. The State has also adopted rules that make it easier for AI/AN MA and MinnesotaCare recipients enrolled in managed care organizations to obtain their care through IHS and Tribally operated health facilities. A recent Minnesota law allows any AI/AN – including those enrolled in PMAP+ – to receive health services at any Tribal clinic on a fee-for-service basis. Additionally, any Tribal clinic can be a primary care provider for AI/ANs enrolled in the PMAP+ program.

There appears to be little relationship between County human services staff and Tribal staff in the sites we visited, except in isolated instances where AI/AN health facility staff have said they have made extensive effort to establish DHS County contacts. Tribal representatives generally said they would rather side-step County governments and work with the State to run their own programs, although Tribal resources are unavailable for most Minnesota Tribes to accomplish this.

Based on our interviews, there appears to be "serious" under-enrollment of AI/ANs in Minnesota in the MA and Medicare Savings Programs, as well as in Medicare Part B. Most of those interviewed, except for the State DHS interviewees, did not discuss the MinnesotaCare program because they felt AI/AN populations in their area would not qualify. Interviewees stated most ineligibility was due either to low incomes that would qualify AI/ANs in their area for MA instead or because AI/ANs in their area have employer-sponsored insurance. DHS interviewees believe that most AI/ANs in Minnesota are aware of the MA and MinnesotaCare programs but that eligible persons do not have detailed knowledge of them. Mille Lacs Band members constitute an exception to MA and Medicare Savings Programs AI/AN under-enrollment in the State, primarily because Mille Lacs administers its own MA program. Additionally, both Mille Lacs and Fond du Lac pay Medicare Part B premiums for Tribal members who cannot, or will not, pay the premiums, substantially reducing under-enrollment in Medicare Part B among Tribal members.

The most common enrollment barrier themes among those interviewed include a belief in the Federal Trust Responsibility to provide health care; lack of consumer education about the benefits of the public insurance programs for individuals and communities; lack of continuing professional staff training about details of, and changes to, the programs; and resistance to sharing information with strangers (particularly at County DHS offices). Also, as in many other States, lack of reliable transportation was often mentioned as a significant barrier to program enrollment and health care services. Interviewees said that AI/ANs living in urban areas, and in the more isolated rural areas, appear to be more likely than those living in other areas of Minnesota to have pockets of program under-enrollment in large part due to transportation barriers.

Tribes such as Fond du Lac and Mille Lacs, which are relatively financially well-off because of casino and other business revenues, have had the will and resources to invest in health facility screening, application assistance, billing, and accounting systems that interviewees said have significantly increased third-party revenues. However, many Tribes in Minnesota do not have such resources. In addition, we were told that program outreach outside of health facilities is very limited by any organization, including the State. Interviewees generally believe that AI/ANs who do not regularly use health facilities – either IHS, Tribally operated, or Contract Health Services – may constitute another group of under-enrolled people in the State.

Despite State-funded provision of training and consumer education about MA, MinnesotaCare, and Medicare, all interviewees agreed that there is substantial additional need for this across the State, as well as for Tribally-directed application assistance and case management through Tribal advocates. The State currently provides few regularly scheduled training and is facing significant budget shortfalls. Some exceptions are Wisdom Steps program training and a new project beginning this year by the Children's Defense Fund-Minnesota under

a Robert Wood Johnson Foundation "Covering Kids" grant. The State, Tribes, and urban-area health care providers interviewed all stated that CMS and IHS need to take a much larger role in providing funds for professional training and consumer education, as well as support for Tribal and urban-area AI/AN advocates which they said would be most effective for providing one-on-one application and case management assistance. Statewide organization interviewees also acknowledged that Tribal operation of public benefits programs would likely improve program enrollment to a significant extent. However, they also agreed that the lack of funds for most Tribes to establish the infrastructure and systems needed to run their own programs, as well as CMS waiver support, are serious obstacles to accomplishing this.

According to nearly all interviewees, consumer education – including outreach outside of IHS- and Tribally-operated health facilities in the State – needs to focus on why AI/ANs should sign up for MA, MinnesotaCare, Medicare Part B, and the Medicare Savings Programs in spite of their belief in the Federal Trust Responsibility to provide health care to AI/ANs. This education should focus on both benefits to individuals and to communities.

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Tribal, and County organizations developed to address issues related to access to health care coverage. The pilot is planned to be operated out of the Bemidji IHS Area Office. A pilot outreach worker will provide information and application assistance to families interested in Minnesota's public programs at locations throughout the County. Specific attention will be paid to the County's AI/AN population and to rural families. In addition to providing application assistance, the Beltrami pilot will coordinate enrollment and retention efforts with County and Tribal programs and work with other organizations in the County to disseminate information about health coverage programs and educate parents about the importance of coverage in keeping their families healthy (http://www.cdf-mn.org/ CKAFpilot.html#Anchor-Minneapolis-49575, accessed January 31, 2003).

# APPENDIX V.A: MINNESOTA SITE VISIT CONTACT LIST

# Fond du Lac Band of Ojibwe

Name	Title	Address	Phone	Email address	
Phil Norrgard	Director, Human Services Division, Fond du Lac Lake Superior Band of Chippewa	Fond du Lac Band of Ojibwe, 927 Trettle Lane, Cloquet, MN. 55720	218-879- 1227	phil.norgard@fdlrez.com	
Chuck Walt	Associate Director, Human Services Division, Fond du Lac Lake Superior Band of Chippewa	927 Trettle Lane, Cloquet, MN. 55720	218-879- 1227,	chuck.walt@fdlrez.com	
Janette Sudderquist	Min-No-Aya Win Clinic Billing Department	927 Trettle Lane, Cloquet, MN. 55720	218-879- 1227	janette.sudderquist@fdlrez.com	
Rod King	Medical Social Worker, Min-No- Aya-Win Health Clinic, Cloquet; Wisdom Steps Representative	Fond du Lac Band of Ojibwe, 927 Trettle Lane, Cloquet, MN. 55720	218-878- 2131	rodking@fdlrez.com	
Chuck Ells	Medical Social Worker, Center for AI/AN Resources Diluth	Fond du Lac Band of Ojibwe, 927 Trettle Lane, Cloquet, MN. 55720	218-726- 1370 ext. 4130	chuckellis@fdlrez.com	
Norma Blake	Title VI Senior Services Director	Not Available	Not Available	Not Available	
Jean Mulder	Tribal Executive Director	1720 Big Lake Road, Cloquet, MN. 55720	218-879- 4593	jeanmulder@fdlrez.com	
Velvet Linden	Tribal CommunityServices Director	1720 Big Lake Road, Cloquet, MN. 55720	218-879- 4593	Velvet Linden	

# Mille Lacs Band of Ojibwe

Name	Title	Address	Phone	Email address
Sharon Gislason	Tribal Health Director	Mille Lacs Band of Objibwe, 43408 Oodena Drive, Onamia, MN. 56359	320-532-4163	Not Available
Connie Saaristo	Circle of Health Director (formerly Social worker at Fond du Lac, MN Medicaid and	Mille Lacs Band of Objibwe, 43408 Oodena Drive, Onamia, MN. 56359	320-532-5358	connie@mlcircleofhealth.com

Name	Title	Address	Phone	Email address
	Dept. of Health Employee)			
Cathy Easter	Medical Social Worker, Elder Advocate	Mille Lacs Band of Objibwe, 43408 Oodena Drive, Onamia, MN. 56359	320-532-4163 X7537	Not Available
Nora Benjamin	Title VI Senior Services Director	Mille Lacs Band of Objibwe, 43408 Oodena Drive, Onamia, MN. 56359	320-532-7494	norab@millelacsojibwe.nsn.us
Pam Pewash	Director of Tribal Community Support Services	Mille Lacs Band of Objibwe, 43408 Oodena Drive, Onamia, MN. 56359	320-532-4163	Not Available
Frances Davis	Contract Health Services	Mille Lacs Band of Objibwe, 43408 Oodena Drive, Onamia, MN. 56359	320-532-4163	Not Available
Patient Benefits Coordinators	Ne-Ia-Shing Health Clinic	Mille Lacs Band of Objibwe, 43408 Oodena Drive, Onamia, MN. 56359	320-532-4163	Not Available
Five AI/AN Elders	Mille Lacs AI/AN Assisted Living Center	Mils Lacs Band of Objibwe, 43475 Oodena Drive, Onamia, Mn. 56359	320-532-4163	Not Available

# Minneapolis/St. Paul Urban Area

Name	Title	Address	Phone	Email address
Sue Bowstring	Housing Manager, Elders Lodge, St. Paul	Elders Lodge, St. Paul Minnesota	651-778-2501	Sue Bowstring
Margaret Monroe	Licensed Social Worker, Minneapolis Indian Health Board	Indian Health Board of Minneapolis,1315 E. 24th Street, Minneapolis, MN. 55404	612-721-9873	Margaret Monroe
Judy Azure	Director, Minneapolis Indian Health Board	Indian Health Board of Minneapolis, 1315 East 24th Street, Minneapolis, MN. 55404	612-721-9800	Judy Azure
Jeff Spartz	CEO, Administrator, Hennepin County	Hennepin County Medical Center. 701 Park Avenue,	612-347-2340	Jeff Spartz

	Medical Center	Minneapolis, MN. 55415		
Pam Zimmerman	Program Manager, Senior Linkage Line and Health Insurance Counseling, Metropolitan Area Agency on Aging	Metropolitan Council on Aging, 1600 University Avenue West, Suite 300, Minniapolis, MN. 55104	651-641-8612	Pam Zimmerman

# **Statewide Organizations**

Name	Title	Address	Phone	Email address
Mary Snobl	Minnesota Board on Aging Indian Elder Desk;Wisdom Steps Coordinator	Minnesota Board on Aging, 444 Lafayette Road, St. Paul, MN 55155- 3843	651-297- 5458	Mary Snobl
Helen Cummings	Elder's Advocate, Leech Lake Elders Division	6530 Highway 2, NW, Cass Lake, MN 56633	218-335- 3792	Helen Cummings
Jenny Jenkins	Bemidji IHS Area Office	Leech Lake Service Unit 317 7th Street NW, Cass Lake, MN 56633	218-335- 3205	Jenny Jenkins
Vernon LaPlante	Minnesota Department of Human Services Tribal Relations Representative	Minnesota Department of Human Services, 444 Lafayette Road North, St. Paul, MN. 055155	651-296- 4606	vernon.laplante@State.us
Kathleen Vanderwall	Minnesota Department of Human Services Tribal Relations Specialist	Minnesota Department of Human Services, 444 Lafayette Road North, St. Paul, MN. 055155	651-282- 3720	kathleen.vanderwall@State.mn.us
Ann Berg	Manager, CMS Relations, Minnesota Department of Human Services	Minnesota Department of Human Services, 444 Lafayette Road North, St. Paul, MN. 055155	651-296- 0642	ann.berg@State.mn.us
Sandy Burge	Manager, Negotiation, Tribal, and Waiver Relations, Minnesota Department of Human Services	Minnesota Department of Human Services, 444 Lafayette Road North, St. Paul, MN. 055155	651-296- 7429	sandy.burge@State.mn.us
Norby Blake	Indian Programs Specialist, Chemical Dependency, Minnesota Department of Human Services	Minnesota Department of Human Services, 444 Lafayette Road North, St. Paul, MN. 055155	Not Available	Not Available
Donna Isham	Special Assistant to the Director,	Minnesota Department of Human Services,	651-582- 1842	donna.isham@State.mn.us

Name	Title	Address	Phone	Email address
	Chemical Dependency, Minnesota Department of Human Services	444 Lafayette Road North, St. Paul, MN. 055155		
Betty Poitra	American Indian Programs Specialist, Mental Health, Minnesota Department of Human Services	Minnesota Department of Human Services, 444 Lafayette Road North, St. Paul, MN. 055155	651-582- 1826	betty.poitra@State.mn.us
Jane Martin	Health Care Eligibility and Access Division, Minnesota Department of Human Services	Minnesota Department of Human Services, 444 Lafayette Road North, St. Paul, MN. 055155	651-297- 1183	jane.martin@State.mn.us
Gretchen Haug	Great Lakes Inter-Tribal Epidemiological Center	Great Lakes Inter- Tribal Epidemiological Center, P.O. Box 9, 2932 Hwy. 47 North, Lac du Flambeau, WI. 54538	715-588- 3324	ghaug@glitc.org
Paul Reynolds	Great Lakes Inter-Tribal Epidemiological Center	Great Lakes Inter- Tribal Epidemiological Center, P.O. Box 9, 2932 Hwy. 47 North, Lac du Flambeau, WI. 54538	715-588- 3324	preynolds@glitc.org

#### CHAPTER VI. MONTANA

#### BACKGROUND

#### Overview

This Case Study Report presents background information and findings from a seven-day site visit to Montana conducted in Billings, the Crow Reservation, the Fort Belknap Reservation, and the Rocky Boy's Reservation. The site visit team included Kathryn Langwell and Tom Dunn of Project HOPE and Mary Laschober of BearingPoint (who attended only the Crow Agency/Billings portion of the site visit). Interviews were conducted with the Montana Department of Public Health and Human Services (DPHHS), DPHHS eligibility and enrollment staff, urban Indian health facility staff, Tribal health directors and staff, Tribal council members, Indian Health Service (IHS) Billings Area Office and IHS Service Unit staff, and Tribal members on the three Reservations.

An earlier version of this Case Study Report was reviewed by the Centers for Medicare & Medicaid (CMS) Project Officer and by CMS staff, for accuracy and clarity. Subsequently, the Draft Case Study Report was sent to each of the Montana organizations that participated in the site visit, with a request that the draft be reviewed for accuracy and that comments and additions would be incorporated into the Case Study Report. Comments were received from the representatives from the Fort Belknap Reservation, representatives from the Rocky Boy's Reservation, and from staff at the IHS Crow Agency Service Unit. In addition, State Government staff provided comments on the Draft Report. These comments have been incorporated into this Revised Draft Case Study Report.

The comments and recommendations contained within this Report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or the feasibility of the recommendations. Neither the comments nor the recommendations contained within this Report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services, the Indian Health Service, or the State.

#### Montana AI/AN Population and Location

Within its borders, Montana has 10 Federally Recognized Tribes on seven Reservations and one Tribe that has applied for Federal recognition (Table 1). Montana is part of the IHS Billings Area Office that serves Montana and Wyoming. In 2000, 66,320 AI/ANs resided in Montana, <sup>172</sup> comprising 7.4 percent of the State's total population.

With a Statewide population density of 6.2 people per square mile, <sup>173</sup> much of Montana is classified as rural/frontier, with 54 percent of the population residing in urban areas and 46

U.S. Census Bureau, Census 2000 Summary File, http://factfinder.census.gov/bf/lang=en\_vt\_name=DEC\_2000\_SF1\_U\_DP1\_geo\_id=04000US30.html, accessed 6/6/03.

U.S. Census Bureau, Census 2000 Summary File, http://factfinder.census.gov/bf/ lang=en vt name=DEC 2000 SF1 U GCTPH1 US9 geo id=01000US.html, accessed 6/6/03.

percent residing in rural areas of the State.<sup>174</sup> The geography, travel distances between communities, and harsh winters in Montana affect health services accessibility and create a number of impediments to enrollment in Medicaid, SCHIP, and Medicare.

Tribe	Reservation	Reservation Enrolled Population Total Reservation Population		AI/ANs as a Percent of Total Reservation Population	
Blackfeet	Blackfeet	14,000 enrolled 8,507 live on Reservation	10,100	84%	
Confederated Salish and Kootenai	Flathead	6,950 enrolled, 4,500 live on Reservation	26,172	17%	
Chippewa-Cree	Rocky Boy's	2,500 enrolled, 1,542 live on Reservation	1,605	96%	
Assiniboine and the Gros Ventre	Fort Belknap	5,000 enrolled 2,790 live on Reservation	2,959	95%	
Sioux divisions of Sisseton/Wahpetons, the Yantonais, and the Teton Hunkpapa, plus the Assiniboine bands of Canoe Paddler and Red Bottom	Fort Peck	10,700 enrolled, 6,391 live on Reservation	10,321	62%	
Crow	Crow	6,757 enrolled, 5,165 on Reservation	6,894	75%	
Northern Cheyenne	Northern Cheyenne	4,029 live on Reservation	4,470	90%	

Source: U.S. Census Bureau, Census 2000 Redistricting Data (Public Law 94-171) Summary File, Matrices PL1 and PL2, http://factfinder.census.gov/bf/\_lang=en\_vt\_name=DEC\_2000\_PL\_U\_GCTPL\_ST5\_geo\_id=04000US30.html (accessed May 23, 2003).

Source: http://indiannations.visitmt.com/ (accessed May 21, 2003).

Data on the proportion of the population that is AI/AN in each of the primary counties where Reservations are located in Montana are presented in Table 2. Some Reservations extend over two or more counties. Table 2 presents data for the Reservation County that has the highest number of people who reported race as AI/AN only or in combination with another race. <sup>176</sup> The proportion of the County population who report AI/AN race ranges from 64 percent on the

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Census 2000 Summary File 3, http://ceic.commerce.State.mt.us/C2000/UA\_UC/urban\_rural\_cty\_sf3.xls (accessed June 6, 2003).

<sup>&</sup>lt;sup>175</sup> Enrolled is the number of AI/ANs officially recognized as members of the tribe by Tribal leadership; the requirements and mechanism for recognition vary by tribe.

<sup>176</sup> Race is self-identified in the Census and a substantial number of people who indicate AI/AN as their race also self-identify as being of one or more other races. Currently available Census data do not permit identification of individuals who are members of a Federally Recognized Tribe, although these data will be available within the next year. For purposes of Table 2, we chose to include all people who identified themselves as AI/AN, either solely or in combination with other races, in the 2000 Census in order to estimate the maximum proportion of the County population that would be affiliated with the Tribes residing on the specific Reservation.

Blackfeet Reservation (located next to Glacier National Park near the Canadian border) to 19 percent on Rocky Boy's Reservation (located in north central Montana). Median age of the total population in Montana is 37.5 years. The median age in primary Reservation counties is several years younger, with the exception of the County where the Flathead Reservation is located.

Table 2. Percent AI/AN Population and Median Age in Primary Reservation Counties in Montana

	Black- feet	Flathead	Rocky Boy's	Fort Belknap	Fort Peck	Crow	Northern Cheyenne	МТ	US
Total AI/AN population	63.9%	26.8%	19.0%	46.7%	57.8%	62.0%	34.1%	7.4%	1.5%
Median age	30.6	38.2	34.5	34.4	32.3	29.8	34.5	37.5	35.3

Source: U.S. Census Bureau, Census 2000 Redistricting Data (Public Law 94-171) Summary File, Matrices PL1, PL2, PL3, and PL4.Note: Some Reservations extend over multiple counties. The data in this Table is drawn from the Reservation County that has the largest number of persons who reported AI/AN race, alone or in combination with one or more other races, on the 2000 Census. The Census Bureau had not yet released public use files providing data on Reservation populations, at the time this report was prepared, and it was not possible to construct population profiles for individual Reservations. It is anticipated that 2000 Census data on Reservation areas will be released in December 2003.

Per capita income in Montana counties with Reservations is lower than average per capita income in the State. The Crow Reservation had the lowest per capita income, among Reservation counties, at \$10,792; the Flathead Reservation had the highest per capita income at \$15,173, compared with an average per capita income in Montana of \$17,151.

The percent of households with incomes below the Federal Poverty Level (FPL) in 1999 was highest on the Fort Peck and the Northern Cheyenne Reservations, which had 27.6 percent of households below the FPL. Fourteen percent of households on the Flathead Reservation had incomes below the FPL, compared with 10.5 percent for all of Montana.

Households with children under age 18 had the highest rates of income below the FPL, while individuals aged 65 and older had the lowest rates, both for Reservation counties and for Montana's overall population.

Table 3. Economic Characteristics in Primary Reservation Counties in Montana, 2000

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	Black- feet	Flathead	Rocky Boy's	Fort Belknap	Fort Peck	Crow	Northern Cheyenne	MT	US
1999 Per Capita Income	\$11,597	\$15,173	\$14,935	\$12,101	\$11,34 7	\$10,792	\$11,347	\$17,151	\$21,587
Percent below 1	poverty level	1999							
All Families	23.5%	14.0%	15.3%	23.4%	27.6%	23.7%	27.6%	10.5%	9.2%
Families With related children under 18 years	29.2%	23.1%	22.9%	32.4%	35.9%	31.2%	35.9%	16.4%	13.6%
Individuals 18-64:	24.3%	16.0%	16.3%	23.9%	27.4%	24.7%	27.4%	13.1%	10.9%
Individuals 65 and older:	20.1%	8.3%	9.0%	19.9%	15.1%	20.1%	15.1%	9.1%	9.9%

Source: U.S. Census Bureau, Census 2000 Redistricting Data (Public Law 94-171) Summary File, Matrices PL1, PL2, PL3, and PL4.Note: Some Reservations extend over multiple counties. The data in this Table are drawn from the Reservation County that has the largest number of persons who reported AI/AN race, alone or in combination with one or more other races, on the 2000 Census. The Census Bureau had not yet released public use files providing data on Reservation populations, at the time this report was prepared, and it was not possible to construct population profiles for individual Reservations. It is anticipated that 2000 Census data on Reservation areas will be released in December 2003.

Note: Poverty data in this table isolates AI/AN statistics from the rest of the Reservation County's population.

## AI/AN Health Services in Montana 1777

The Billings Area IHS provides services to over 60,000 AI/ANs who reside in Montana and Wyoming. There are seven IHS Service Units in Montana, located on the Blackfeet Reservation, Flathead Reservation, Fort Peck Reservation, Northern Cheyenne Reservation, and Rocky Boy's Reservation. The Confederated Salish and Kootenai Tribes have chosen to manage the Service Unit on the Flathead Reservation and the Chippewa Cree Tribe manages the Service Unit on the Rocky Boy's Reservation under self-governance compacts. The other five Service Units in Montana are operated under IHS direct service arrangements.

All Service Units provide ambulatory, emergency, dental, environmental health, community health, and preventive services. Hospital inpatient and outpatient services are provided at the Blackfeet, Crow, and Fort Belknap Service Units. The Flathead Service Unit provides pharmacy, dental, and some physician services and has contractual arrangements with physicians and hospitals in local communities for all other services.

The Billings Area IHS also provides some funding for five Urban Indian Health Centers located in Billings, Butte, Great Falls, Helena, and Missoula. Three of the Urban Indian Health Centers provide primary medical services and limited mental health services; all five provide outreach and referral, health education, transportation, and substance abuse services. The urban

<sup>&</sup>lt;sup>177</sup> www.ihs.gov, accessed May 20, 2003.

centers' transportation services are structured to provide access both to Urban Indian Health Centers and to Reservation-based health programs that are within a reasonable travel distance.

#### **Overview of Montana State Government**

The State of Montana does not have a Tribal office and/or an AI/AN liaison. However, the Governor's Office does address Tribes in a Statement of "Strategic Objectives." Specific reference to the Tribes include:

- Expand economic development opportunities on Montana's seven Reservations in partnership with Tribal Governments and the Federal Government.
- Build and expand relationships between the State and Tribal Governments:
- Encourage and enhance communications between State programs and Tribal governments;
- Work with Native American Veterans through visits from Montana's Department of Military Affairs to assist in obtaining entitlements and benefits.
- Continue to develop and encourage advisory councils within departments to work with Tribal governments.
- Work with Tribal economic development commission to strengthen economic opportunities on Reservations;
- Travel to Montana's Reservations and meet with Tribal leaders; and
- Encourage Native American representation on advisory councils and boards.

In 2003, the Montana legislature passed House Bill 608. This Act relates to government-to-government relationships between Montana Indian Tribes and the State of Montana. It provides for Tribal consultation in the development of State agency policies that directly affect Indian Tribes, authorizes certain State employees to receive annual training on history and legal issues relating to Tribes, provides for annual meetings between State and Tribal officials, and requires an annual report by State agencies on policy and regulatory changes that affect Montana Indian Tribes.

# **Overview of Montana State Medicaid Program** 179

The largest of Montana's medical assistance programs is Medicaid, which covers an average of 60,000 people a month. Medicaid is especially important for children and pregnant women; each month Medicaid covers one in ten Montana children. Medicaid also pays for almost 40 percent of the births in Montana. Currently, over 11,000 providers are enrolled in Medicaid, including every Montana hospital and almost every physician. Income eligibility

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http://www.discoveringmontana.com/gov2/css/goals/govstrategy.asp, accessed June 6, 2003.

<sup>&</sup>lt;sup>179</sup>http://www.dphhs.State.mt.us/hpsd/medicaid/pdf/sfy 2003\_budget.pdf, accessed May 22, 2003.

http://www.dphhs.State.mt.us/hpsd/medicaid/pdf/general.pdf, accessed May 22, 2003.

levels for the major Montana Medicaid programs and Montana's State Children's Health Insurance Program (SCHIP) are shown in Table 4, below.

Table 4. Annual Income Eligibility Levels Montana Medicaid and SCHIP Programs, 2003<sup>181</sup>

Family Size	Medicaid 100% FPL (children age 6 and older)	Medicaid 133% FPL (children age 5 and under)	SCHIP 150% FPL	SSI 175% FPL	CSHS 200% FPL	Categorically Needy <sup>a</sup>	Medically Needy
1	\$8,980	\$11,943	\$13,470	\$15,715	\$17,960	\$6,624	na
2	12,120	16,120	18,180	21,210	24,240	9,948	\$6300/couple
3	15,260	20,296	22,890	26,705	30,520	Na	na
4	18,400	24,472	27,600	32,200	36,800	Na	na
5	21,540	28,649	32,310	37,695	43,080	Na	na
6	24,680	33,318	37,020	43,190	49,360	Na	na
7	27,820	37,557	41,730	48,685	55,640	Na	na
8	30,960	41,796	46,440	54,180	61,920	Na	na
9	34,100	46,035	51,150	59,675	68,200	Na	na
10	37,240	50,274	55,860	65,170	74,480	Na	na

<sup>&</sup>lt;sup>a</sup> The Categorically Needy Income Standards are the benefit amounts paid by the Social Security Administration to Supplemental Security Income (SSI) cash recipients

The Montana Medicaid program offers two distinct levels of coverage categorized as either "FULL" or "BASIC," and each has different eligibility requirements and coverage levels as follows: 182

- FULL benefits are provided to enrollees who are eligible for all services that Medicaid covers if medically necessary. The following individuals may be eligible for FULL benefits: pregnant women, children age 20 and under, and adults who are blind, age 65 or older or disabled and anyone receiving Supplemental Security Income (SSI).
- BASIC benefits are provided to enrolled people in other Medicaid categories who are eligible for some, but not all, services. Medicaid does NOT pay for services not covered, except in the case of an emergency or where a job requires the services. The following individuals may be eligible for BASIC benefits: adults receiving Medicaid over age 20 who are not pregnant, not blind, under age 65, and are not disabled or receiving SSI.

BASIC benefits do not pay for, for example, audiology (hearing aid exams and hearing aids) \* EFE; dental services (except emergencies) \* EFE; durable medical equipment and supplies (except for insulin-dependent diabetics, ostomy supplies, home infusion therapy, oxygen and prosthetics) \* EFE; eyeglasses and routine eye exams \* EFE; or personal assistance services \* EFE. 183

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<sup>&</sup>lt;sup>181</sup> 2003 data table faxed from the director of the Montana SCHIP program.

Source http://www.dphhs.State.mt.us/hpsd/medicaid/medrecip/medinfo/medinfo.pdf (accessed May 22, 2003).

<sup>&</sup>lt;sup>183</sup> EFE means "Essential For Employment": This service may be covered under BASIC benefits if it is "essential for employment."

The PASSPORT To Health Program is the primary care case management (PCCM) program for Montana Medicaid. Clients choose a primary care provider who manages the client's health care needs. Approximately 70 percent of all Montana Medicaid clients are on this program. Medicaid clients who are not enrolled into PASSPORT To Health are those who: are in a nursing home or other institution; have both Medicare and Medicaid coverage; are classified as medically needy; are receiving Medicaid for less than three months; are on the Restricted Card Program; live in non-PASSPORT counties; are in subsidized adoption; have only retroactive eligibility; and/or are receiving Home and Community-Based Waiver Program services.

Medicaid ID cards are issued monthly and list all eligible family members (up to five clients per card). Providers are reminded that Medicaid eligibility may change from month to month and, therefore, it is important to check the card during each visit to ensure the client is eligible for services that day.<sup>184</sup>

Care rendered to newborns can be billed under the newborn's temporary Medicaid ID number (assigned by the mother's local office of public assistance) until a permanent ID number (social security number) becomes available. The hospital or the parents may apply for the child's social security number. Parents are responsible for notifying their local office of public assistance when they have received the child's new social security number.

To encourage prenatal care, uninsured pregnant women may receive "presumptive eligibility" for Medicaid. If the client presents a *Presumptive Eligibility Notice of Decision*, the provider is instructed to call a 1-800 number to confirm presumptive eligibility. Presumptive eligibility does not cover inpatient hospital services, but does include all other applicable and covered Medicaid services. Designated providers determine presumptive eligibility and give the client a *Presumptive Eligibility Notice of Decision*.

The medically needy program provides coverage for people who have an income level that is higher than Medicaid program standards but who have high medical expenses relative to income and who spend down to Medicaid eligibility on a monthly basis. Eligible individuals are responsible for paying for services received before eligibility begins and Medicaid pays for remaining covered services for that month or part of the month. Those eligible for this program also have a "cash option" where they can pay a monthly premium to Medicaid instead of making payments to providers, and have Medicaid coverage for the entire month.

The Montana Breast and Cervical Cancer Treatment Program provides Basic Medicaid coverage for qualified women who have been screened through the Montana Breast and Cervical Health Program (MBCHP) and diagnosed with breast and/or cervical cancer or a pre-cancerous condition. Clients enrolled in this program are provided a Medicaid ID card showing "Basic" coverage.

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<sup>184</sup> http://www.dphhs.State.mt.us/hpsd/medicaid/pdf/general.pdf,accessed May 22, 2003.

For Qualified Medicare Beneficiaries (QMB) under the Medicare Savings Programs, <sup>185</sup> Medicaid pays Medicare premiums and some or all of their Medicare coinsurance and deductibles. Montana QMB clients may or may not also be eligible for Medicaid benefits. <sup>186</sup> QMB Only enrollees receive payments only toward Medicare coinsurance and deductibles. QMB/Medicaid enrollees receive full Medicaid coverage that supplements and expands Medicare coverage. If a service is covered by Medicare but not by Medicaid, Medicaid will pay all or part of the Medicare deductible and coinsurance. If a service is covered by Medicaid but not by Medicare, then Medicaid is the primary payer. Specified Low-Income Medicare Beneficiaries (SLMB) receive coverage from Medicaid only for the cost of the Medicare Part B premium. Income levels to qualify for QMB and SLMB coverage are shown in Table 5.

Table 5. Medicare Savings Programs, Annual Income Eligibility, 2003

Family Size	QMB	SLMB
Qualified Individual	\$8,868	Between \$8,868.01 and \$10,632
Qualified Couple	\$11,940	Between \$11,940.01 and \$14,328

In November 2002, the State utilization reports suggested that Medicaid enrollment and Medicaid costs were rising and that spending at the current rate would lead to a deficit before the end of the fiscal year, June 30, 2003. To avoid a deficit situation, program and policy changes were designed to reduce Medicaid expenditures to the appropriated funding level. In addition to changes in Medicaid services, the Department also limited eligibility for some individuals in the Aged, Blind and Disabled category. Eligibility changes became effective February 1, 2003.

# **Montana SCHIP Program**<sup>187</sup>

Montana's SCHIP program is a low-cost, private health insurance plan that provides health insurance coverage to eligible Montana children who have no insurance and who are <u>not</u> eligible for Medicaid. Financial eligibility is based on a family's gross income, with no asset or resource test requirement. Due to the FY2003 enrollment cap of 9,550 children imposed by funding levels of the State legislature, eligible children may be placed on a waiting list when eligibility is determined. As of May 22, 2003, 704 children were on this waiting list.

Applications for SCHIP are available in all Montana communities through a variety of sources, including County health departments, health care facilities, WIC offices, Head Start facilities, IHS facilities and other community locations, or are available by mail through calling a toll-free number.

<sup>1</sup> 

The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

http://www.dphhs.State.mt.us/hpsd/medicaid/pdf/general.pdf,accessed May 22, 2003.

http://www.dphhs.State.mt.us/hpsd/pubheal/chip/index.htm, accessed May 22, 2003.

<sup>&</sup>lt;sup>188</sup> Children become disenrolled when they reach the age of 19 years, receive other health care coverage (including Medicaid), move away from Montana, or if parents do not renew their children's SCHIP insurance.

Eligibility is determined according to the following criteria:

- Children under age 19.
- Montana residents.
- United States citizens or qualified aliens.
- Not currently insured or covered by health insurance in the past three months (some employment-related exceptions apply).
- Not eligible for Medicaid.
- Parents not employed by the State of Montana.
- Household meets income guidelines (see Table 4, above).

Parents share in the cost of their children's health care by making a co-payment when services are received. Total co-payments for any family may equal no more than \$215 per family per "benefit year" (Oct. 1 through Sept. 30). The following lists co-payment criteria and amounts:

- No co-payment for well-baby or well-child care, including age-appropriate immunizations.
- No co-payment for dental services.
- \$25 each inpatient hospital visit.
- \$5 each emergency room visit.
- \$5 each outpatient hospital visit.
- \$3 each physician visit.
- \$3 each generic prescription drug.
- \$5 each brand-name prescription drug.
- The State does not require cost-sharing for AI/AN children.

Montana's Department of Public Health and Human Services contracts with Blue Cross Blue Shield (BCBS) to provide health insurance to children enrolled in SCHIP. The Department pays a per member per month premium to BCBS for each enrolled child. BCBS provides SCHIP enrollees with an insurance identification card, an enrollee handbook describing how to use the insurance, and a list of network doctors, dentists, and other health providers.

Another source of medical assistance in Montana is the Children's Special Health Services (CSHS) program. This program is designed to assist families by paying medical costs

and finding resources for children with special health care needs. However, a child must first apply for Medicaid and/or SCHIP. If the child does not meet either program eligibility requirements, then a child's CSHS eligibility is based on 1) family income and 2) the child's diagnosis. Covered conditions include: heart, orthopedic, cleft/craniofacial, neurologic (such as a seizure), Spina bifida, urological, developmental delay (limited assistance), and preventive care for chronic conditions including diabetes, asthma and cystic fibrosis.

#### **DESCRIPTION OF SITE VISIT**

#### Overview

Prior to conducting the site visit to Montana, the site visit team contacted Jonathan Windy Boy, a member of the project's Technical Expert Panel and a Tribal Council member of the Chippewa Cree Tribe from Rocky Boy's Reservation in Montana, to discuss the Montana site visit and obtain recommendations of specific Tribes to visit. Mr. Windy Boy urged that we visit Rocky Boy's Reservation and recommended the Fort Belknap Reservation as a site. Discussions were also conducted with the Executive Director of the Montana-Wyoming Tribal Leaders Council to obtain background information on communities the site visit team were considering in Montana, potential key contacts, and specific issues that should be addressed in the site visit. Further advice and suggestions were obtained from Jim Lyon, the CMS Native American Contact for Region VIII, and from Frank Ryan, project consultant and a member of the Gros Ventre Tribe from the Fort Belknap Reservation. For each of these discussions, the project team initially provided the individual(s) interviewed with a copy of the project description and summarized the goals of the site visits. Interviewees were then asked to recommend two Tribes/Reservations and one urban area with a facility that provides direct medical services. In addition, the site selection criteria included, where possible, one Tribe/Reservation served directly by an Indian Health Service facility and one served by a Tribally managed health facility. The project team also emphasized that, given that only three days were budgeted for visiting two Reservations and an urban area, travel distances were also of some importance.

Based on these discussions and the recommendations received, the project team selected the Rocky Boy's Reservation (with a Tribally managed health facility) in north central Montana and the Crow Reservation (with an Indian Health Service health facility) in eastern Montana as visit sites. However, after we had initiated contact with Tribal Chairmen at these two sites, Mr. Jonathan Windy Boy again strongly urged us to expand the site visit to include Fort Belknap. Because Fort Belknap is geographically close to Rocky Boy's Reservation, and with the CMS Project Officer's approval, we agreed to include Fort Belknap in the site visit. <sup>189</sup> The Billings Indian Health Board was selected as the urban Indian health facility visit site. In Billings, the site visit team also met with the Montana-Wyoming Tribal Leaders Council and with staff from the Billings Area Office of the IHS.

<sup>&</sup>lt;sup>189</sup> Unfortunately, we were unable to visit Rocky Boy's Reservation and Fort Belknap Reservation together because the Tribal liaison at Rocky Boy's Reservation postponed our site visit a few days before it was to occur. We conducted the Fort Belknap and Crow Reservations site visits during one trip and, several weeks later, made a second trip to Rocky Boy's Reservation for that site visit. As a result, the site visit to Montana took seven days, including travel time.

Because of the distances involved, the site visit team did not travel to the Montana State Capital to meet in-person with State Medicaid and SCHIP staff. Instead, telephone interviews were conducted with these individuals after the site visit team returned home. In addition, the project team also conducted a telephone interview with the Montana director of the Robert Wood Johnson Foundation Covering Kids program. The Covering Kids program was a three-year grant to the State of Montana to develop innovative outreach and enrollment strategies to increase enrollment in the SCHIP program. The Montana Covering Kids program had ended in 2002, before the site visit was conducted.

The process for recruiting participation in the site visit included: 1) a letter was sent to the Tribal Chairmen at Crow, Rocky Boy's, and Fort Belknap Reservations to inform them of the study and that their Tribe had been selected to participate; 2) follow-up telephone calls to the Tribal Chairmen were made to confirm their willingness to participate and to identify a coordinator from the Tribe to assist in scheduling and coordination of the site visit; 3) the project team then worked closely with the Tribal coordinator to determine the individuals who would participate in the scheduled meetings and to obtain background information on unique issues and programs at each site; and 4) a formal agenda was developed for each site visit. For the Billings Indian Health Board, a similar process was followed. Project team members had worked with the Montana-Wyoming Tribal Leaders Council and with the Billings Area Office of the IHS on previous projects, which facilitated the scheduling and coordination of the visit to those organizations. A complete list of individuals who were interviewed during the site visit is provided in Appendix VI.A to this report.

The Montana site visit was the first of ten conducted for this project. Because it was the first, both Mary Laschober and Kathy Langwell, site visit Team Leaders, participated in the site visit. This permitted them to observe the effectiveness of the site visit protocol and to develop a consistent interview and information collection approach that was used in subsequent site visits that they conducted separately.

### **Description of Rocky Boy's Reservation**

The Rocky Boy's Reservation is located in north central Montana, near the Canadian border. It was the last Reservation to be established in Montana (1916) and is home to the Chippewa-Cree. The Chippewa and Cree were the last Tribal groups to settle in Montana, arriving in the late 19<sup>th</sup> century. The two Tribes are intermixed and use the name "Chippewa-Cree" today. 190

About 2,500 members of the Chippewa-Cree Tribe reside on the Rocky Boy's Reservation. Employment on the Reservation is primarily with government agencies and offices, including BIA, IHS, and the public school system. There is also some farming and ranching employment.

<sup>&</sup>lt;sup>190</sup> http://www.lewisandclark.State.mt.us/indianHistory.html, accessed May 24, 2002.

The Chippewa-Cree Tribe has operated its health care system under a self-governance compact with IHS since 1995. The Chippewa Cree Health Center offers medical, dental, and optometry clinics and is a JCAHO-accredited facility. <sup>191</sup>

## **Description of Fort Belknap Reservation**

The Fort Belknap Reservation is located in north central Montana, about 40 miles east of the Rocky Boy's Reservation, near the Canadian border. Approximately 2,800 members of the Assiniboine and the Gros Ventre Tribes reside on the Reservation. Major employers on the Reservation are government agencies, both Federal and Tribal. 192

The IHS provides direct services to the Fort Belknap AI/AN population. The IHS facility provides both ambulatory services and hospital inpatient and outpatient services.

## **Description of the Crow Reservation**

The Crow Reservation is home to the Crow Tribe. The Reservation is located in south central Montana, bordered by Wyoming on the south. Billings, the largest city in Montana, lies about 50 miles north west of the Reservation. Approximately 7,000 enrolled members of the Crow Tribe live on or near the Reservation. <sup>193</sup>

The Crow Tribe has the lowest per capita income of any of the Tribes in Montana. Unemployment is high and the economy depends primarily on government employment. There are large coal deposits in the eastern portion of the Reservation, but these have been exploited on a limited basis. One mine is in operation and provides royalty income and employment to Tribal members. Farming and ranching also provide employment. <sup>194</sup>

The IHS provides health services on the Crow Reservation. IHS facilities include both ambulatory services and hospital inpatient and outpatient services. Because of the close proximity of the Crow Reservation to Billings, the IHS facility also serves a substantial number of urban Indian people who travel around 50 miles to obtain care.

### **Description of the Indian Health Board of Billings**

The Indian Health Board of Billings (IHBB) is one of five Montana Urban Indian Health Centers. It is a non-profit organization under contract to the Billings Area IHS to provide health services to AI/ANs who live in the Billings area. IHBB provides outreach and referral, health education, transportation, and substance abuse treatment services. The transportation component of the program provides services within Billings and from Billings to the Crow Service Unit, which is approximately 50 miles away, to assist AI/ANs in Billings to obtain a range of medical services that are not provided at IHBB.

<sup>&</sup>lt;sup>191</sup> http://rbclinic.rockyboy.org/NewFiles/tour.html, accessed May 24, 2002.

http://lewisandclark.State.mt.us/indianHistory.html, accessed May 24, 2002.

<sup>193</sup> http://tlc.wtp.net/crow.htm, accessed May 24, 2002.

http://www.lewisandclark.State.mt.us/crow.htm, accessed May 24, 2002.

### **Description of Other Organizations Interviewed**

The project team visited two additional organizations in Billings, Montana: The Billings Area Office of the IHS and the Montana-Wyoming Tribal Leaders Council.

The Montana-Wyoming Tribal Leaders Council (TLC)<sup>195</sup> is comprised of Tribal leaders from nine Federally Recognized and one non-Federally Recognized Tribes in Montana and Wyoming. The TLC's operational and governing philosophy is summarized by the following: "In order to preserve and maintain our homelands, defend our Tribe's rights under our Indian Treaties with the United States, to speak in a unified voice, to offer support to our people, to afford ourselves a forum in which to consult each other, to enlighten each other about our peoples, and to otherwise uniformly promote the common welfare of all of the Indian Reservation peoples of Montana and Wyoming." The Montana-Wyoming Tribal Leaders Council also includes the Montana-Wyoming Indian Health Board, with representation on the Board of Directors of the National Indian Health Board.

The Billings Area Office of the Indian Health Service<sup>196</sup> provides services to over 60,000 AI/ANs living on eight Reservations in Montana and Wyoming. Seven IHS Service Units are located in Montana. Five of these Service Units are IHS direct service facilities and two are operated under self-governance compacts. 197 Administrative offices of the Billings Area IHS are located in Billings, Montana.

### FINDINGS: MONTANA MEDICAID AND OTHER STATEWIDE AGENCIES

#### Montana Medicaid Office and Montana SCHIP Office

#### Overview

The project team conducted telephone interviews with Montana Medicaid Office and Montana SCHIP Office staff. Additionally, the project team met in person with two additional organizations in Billings: the Montana-Wyoming Tribal Leaders Council and the Billings Area Office of the IHS.

#### **Montana Medicaid and SCHIP Offices**

The director of the Montana SCHIP program noted there is currently very limited outreach and enrollment activities underway. Because SCHIP program enrollment has been capped and there is already a waiting list, additional outreach and marketing of the program would only add to the waiting list. In addition, the State's budget situation in the Fall of 2002 put the SCHIP program at risk of termination. While the program continues, funds are limited and there is some uncertainty about its future.

http://tlc.wtp.net, accessed May 25, 2003.http://www.ihs.gov, accessed May 25, 2003.

<sup>&</sup>lt;sup>197</sup> The Confederated Salish and Kootenai Tribes compact the Flathead Service Unit and the Chippewa-Cree Tribes compact the Rock Boy's Service Unit.

The director also noted that AI/AN children comprise about 6 to 7 percent of total enrollment and that this was approximately the proportion of AI/ANs in the State. However, she did say that it is possible that this proportion suggests some under-enrollment of AI/ANs, since they may be more likely to be eligible for the program due to lower incomes on average.

### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

### Barriers to Initial Enrollment

When asked about barriers to enrollment for AI/AN children, the SCHIP director said that the following issues contribute to under-enrollment:

- The Medicaid eligibility resource test is complex and particularly difficult for AI/AN people who live in multiple family households, where it is difficult for caseworkers to determine whose income to include when determining eligibility.
- AI/ANs who live in multiple family households may also be concerned that applying for Medicaid may draw the State's attention to unrelated members of the household and result in loss of benefits for some household members.
- There is also a "myth" prevalent among AI/AN people that the State can apply liens against Federal Trust Lands owned by AI/ANs and as a result some AI/ANs are reluctant to apply for Medicaid.
- The relationship between the Tribes and the Medicaid Office, at the State level, has sometimes been strained and this may affect individual AI/AN decisions about application for Medicaid.
- Many AI/AN families rely on IHS and do not consider enrolling in SCHIP until a medical crisis arises and they discover that IHS does not have sufficient funds to cover the cost of the necessary care.
- There is a lack of awareness and understanding of the SCHIP program and of how enrolling children in SCHIP could increase resources available to the IHS.
- When SCHIP funds were first made available, the Tribes in Montana argued that they should receive their share of these funds to administer their own programs. This did not happen and there may be some residual unhappiness leading to reluctance on the part of some Tribes to endorse and market SCHIP.
- In some areas, IHS does not encourage people to enroll their children in SCHIP.
- The facts that the program is capped and that there is a waiting list for eligible children to enroll are barriers to enrollment. First, the waiting list causes a delay in enrollment and

<sup>&</sup>lt;sup>198</sup> A CMS reviewer notes that the Federal government, through Title XXI, is unable by statute to make payments to any entity other than a State.

- receipt of services by children who are eligible. Second, some AI/ANs are aware that the program is capped and do not apply because they do not think they will be approved.
- Although SCHIP is a State program, eligibility determinations are carried out by County caseworkers and there may be variation across counties in how caseworkers interpret the regulations and eligibility criteria.

## Barriers to Maintaining Enrollment

• Many children "drop out" of SCHIP when their parents/guardians do not complete the reapplication process, and this is a major factor in low enrollment rates among some groups. There is no personal follow up with families on re-application and the States does not supply outreach staff with a list of anniversary dates of current enrollees. The State's reason for not sharing information with advocates or with IHS or Tribes is that confidentiality rules do not permit this.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

• Elderly people – AI/AN and non-AI/AN alike – have difficulty understanding and completing enrollment forms and often do not have anyone available to assist them with this process and, as a result, do not apply for Medicaid/Medicare Savings Program enrollment.

## Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

The SCHIP director said that the Robert Wood Johnson Foundation's Covering Kids project in Montana was valuable and effective at designing outreach and enrollment assistance programs, including ones that were targeted to AI/AN families. However, funding ended in 2002 and the State does not have the resources to continue the programs that were developed under Covering Kids.

An interview was also conducted with staff from the Montana Medicaid program. They noted that AI/AN enrollment is about 24 percent of total Montana Medicaid enrollment – almost four times the share that AI/ANs represent of the total Montana population. The Medicaid director stated that she did not think there are significant variations across counties and caseworkers in the interpretation of Medicaid eligibility requirements. There is a detailed resource manual available to every County caseworker that provides eligibility determination information. In addition, Regional Policy Specialists assigned to specific geographic regions act as a resource for caseworkers handling cases that may have unique aspects that are not addressed in the manual. The Regional Policy Specialists also hold training seminars on specific topics and update caseworkers when there are legislative changes in Medicaid.

- One-to-one outreach and enrollment assistance. This type of assistance would require more funding for the program.
- Culturally appropriate outreach and assistance. Culturally appropriate outreach and assistance, both in terms of materials and in terms of the locations where outreach occurs

and assistance is provided. For example, pow-wows and health fairs located on Reservations could be good locations for outreach.

- Advocacy for SCHIP. Tribal leaders, community members, and IHS could advocate for SCHIP and this would likely be more effective than non-AI/AN people advocating for the program.
- Develop targeted media strategies that take into account the situation on different Reservations. For instance, television ads may not be effective in locations where most people have satellite dishes and do not pick up local television stations where these ads run.
- Legal assistance. One suggestion made by the Montana Medicaid office staff that would increase enrollment was directed to providing legal assistance to AI/AN people who are applying for SSDI. The Montana Medicaid office has a small contract with Montana Legal Services to assist to AI/ANs who are applying for SSDI and/or who have been denied SSDI.

## **Montana-Wyoming Tribal Leaders Council**

The Executive Director of the Montana-Wyoming Tribal Leaders Council stressed that enrollment of AI/ANs in Medicaid, SCHIP, and Medicare is critical because Congress has directed that the IHS must generate at least one-third of its revenues from third-party billing. However, most Indian Health Service Units are not able to augment funding through collections to that extent. As a result, Indian Health Service does not have sufficient revenues to meet the health care needs of the AI/AN people they serve.

He said that the working relationships between the Montana Tribes and the State government are not good, particularly at this point as the State is in a budget crisis. The State (at the time of the interview) was proposing serious curtailments of eligibility and of benefits under Medicaid, as well as reducing the cap on SCHIP enrollment.

The most effective way to increase enrollment in these programs, he stated, was for Congress and CMS to develop Tribal Medicaid and SCHIP programs. This would give Tribes control over eligibility, as well as provide them with incentives to identify eligible Tribal members and to assist with enrollment processes. In addition, the administrative funds that

currently go to the State would go to the Tribes to fund outreach and enrollment assistance (which the State is not currently providing to Tribes). 199

## **Billings Area Office of the Indian Health Service**

The project team met with several individuals from the Billings Area Office of the IHS, including the Acting Associate Director, director of Contract Health Services, director of Urban Indian Programs, and the executive director of the Great Falls urban Indian health facility.

Interviewees said that SCHIP, particularly, has low enrollment of AI/AN children in Montana. They said that AI/AN families are generally not interested in applying for SCHIP because they can rely on IHS for most infant and child health care.

The interviewees opined that the State and counties do a good job, however, in getting pregnant women enrolled in Medicaid, but thought that there was under-enrollment of other AI/ANs in Medicaid. They noted that there is substantial variation in third-party revenues collected from Medicaid and Medicare across the Reservations/Service Units in the State but were not sure why this is the case. It could be because there are differences among Tribes and geographic locations in enrollment rates in Medicaid and Medicare. Alternatively, it could be that people who do enroll in these programs choose instead to go to non-IHS providers for their health care. The Billings IHS Office is examining some of these issues to see if there are steps they can take to increase enrollment and/or to encourage those who are enrolled to use IHS as their health care provider.

Interviewees also emphasized that the majority of AI/ANs in Montana live outside a Reservation. Therefore, programs to increase enrollment in Medicaid, SCHIP, and Medicare need to focus on urban areas, as much or more than Reservations. The Billings Office is funding a project with the Great Falls Urban Indian Health Center to conduct door-to-door outreach with AI/ANs to inform them about Medicaid, SCHIP, and Medicare and to provide assistance with enrollment.

The major barriers to enrollment identified by IHS staff include:

3. Assistance with enrollment, appeals, hearings is provided

<sup>&</sup>lt;sup>199</sup> Comments on the Draft Case Study Report received from Fort Belknap representatives included the following: "The Fort Belknap Indian Community agrees with the MT/WY Tribal Leaders Statement and strongly advocates for Congress and CMS to develop Tribal Medicaid and SCHIP programs. The unique government-to-government relationship between the United States and Tribal nations would be greatly enhanced by such an agreement. Tribes could ensure that eligible Tribal members are:

<sup>1.</sup> Identified and determined eligible at the local level.

<sup>2.</sup> Educated on services available.

<sup>4.</sup> Culturally appropriate outreach is provided.

<sup>5.</sup> Lease income is not used to deny eligibility.

<sup>6.</sup> Redetermination is completed timely to maintain enrollment.

Tribal Medicaid programs would permit Tribes to receive administrative funds that the State of Montana now receives. The Medicaid and Medicare reimbursements to Tribes is now 100 percent pass-through under the State of Montana and the Tribes suffer economic disparity and hardship when the State of Montana drastically cuts these funds. The barriers to enrollment identified in the report would be eliminated with such an agreement."

- Many AI/ANs do not see a need to enroll because they have IHS available.
- There is distrust between the Tribes and the State and this causes people not to apply for enrollment in State programs.
- Some County caseworkers resist assisting AI/ANs to enroll in Medicaid and SCHIP because they feel AI/ANs have access to IHS care and do not need to enroll in these programs.
- IHS does not have base data on enrollment of AI/ANs in Medicaid, SCHIP, and Medicare by Reservation and by urban area, making it impossible to identify areas with especially low enrollment rates for targeted outreach and assistance.

Strategies that would be effective suggested by the IHS interviewees include:

- Outreach and education needs to be structured on a one-to-one basis and should emphasize sense of community and the benefits both to the community and individuals of enrollment in Medicaid, SCHIP, and Medicare.
- Increasing the number and availability of benefits coordinators at IHS facilities would be helpful.
- The Tribes and IHS should consider training Community Health Representatives (CHRs) to provide outreach and enrollment assistance, as CHRs are generally effective and trusted by their communities.
- Tribal leaders might consider taking a more active role in communicating the importance of enrollment in Medicaid, SCHIP, and Medicare to the community.

Subsequent to our site visit, the Billings Area Office provided data on Medicaid and Medicare visits and revenues at the Fort Belknap Service Unit and at the Crow Agency Service Unit. Data were not available for the Rocky Boy's facility because it is Tribally managed and does not report third-party revenues to the IHS. The data provided for Fort Belknap and Crow Agency are included in Appendix VI.B to this report.

#### FINDINGS: ROCKY BOY'S RESERVATION

### Overview

The Chippewa-Cree Tribe of the Rocky Boy's Reservation is one of only two Tribes in the Billings IHS Area that manages its own health care system under a Title V self-governance compact. The Tribe receives its allocated funding from IHS and uses these funds to arrange for and deliver health care services to Tribal members. The benefits staff at the Rocky Boy's Service Unit is responsible for screening and assisting patients to apply for and enroll in Medicaid, SCHIP, and Medicare, and the financial staff is responsible for billing and collections from these programs and other private insurance sources.

Mr. Jonathan Windy Boy, a member of the project's Technical Expert Panel, is a member of the Chippewa-Cree Tribal Council and strongly recommended and encouraged the project to conduct the site visit to Rocky Boy's Reservation. Renita Watson, Resource Benefits Coordinator for the Tribally managed Service Unit, coordinated and scheduled the site visit with the project team. Meetings were held with the Assistant CEO of the health facility, Medicaid/SCHIP outreach workers, Community Health Representatives, Contract Health Services staff, billing staff, a counselor from the local school system, vocational rehabilitation staff, and a representative from the Great Falls Social Security office.

In addition, Mr. Alvin Windy Boy, Sr., Chairman of the Tribal Council, Mr. Bruce Sunchild, Vice-Chairman of the Tribal Council, and Mr. Jonathan Windy Boy, Council Member, met with the project team at the beginning of the site visit. The project team provided background information on the study and its objectives to the Tribal leaders, who were supportive of the study and indicated interest in receiving the case study findings and quantitative data when the final report is available.

Interviewees provided background information on the Reservation and on the health care system. They estimated that the number of AI/ANs living on or near the Reservation is approximately 5,000 and stated that this number has been growing in recent years. There are about 550 Chippewa-Cree children enrolled in local schools and 92 percent qualify for Federally subsidized school lunch programs.

Third-party coverage and reimbursements to the Tribal health facility are primarily from Medicaid and Medicare, with a small amount of private health insurance reimbursements. The health facility patient registration protocol requires that each time a patient comes to the facility, health insurance status be discussed.

Some AI/ANs choose to go elsewhere for their health care, particularly if they have third-party coverage. As a result, the health facility does not obtain as much third-party revenue as would be desirable. One reason given by interviewees as a cause for patients going outside the Tribal health facility include a shortage of providers, which leads to long waiting times for appointments and extended waits in the clinic to see the provider. In addition, there has been a series of temporary physicians at the clinic and some patients prefer to see a permanent doctor who can provide continuity of care over a longer time horizon. Interviewees also noted that lack of funding for Contract Health Services is a severe problem for the facility. They estimated that, in most years, the Tribal health facility exhausts its Contract Health Services funds by the middle of the Federal fiscal year.

As well as Medicaid, SCHIP, and Medicare, interviewees were interested in the potential to obtain reimbursements from the Veterans Administration (VA) for eligible Tribal members. The Tribe has been working with the VA to develop a Memorandum of Understanding that would permit the Tribal health facility to provide services to veterans. The nearest VA facility is 100 miles away in Great Falls and this arrangement would facilitate access to care for veterans, as well as offer an additional source of reimbursement to the Tribal health facility.

Interviewees were also enthusiastic about an SSDI outreach program that had been initially conducted on the Blackfeet Reservation and was soon to be repeated on the Fort

Belknap Reservation (only about 50 miles from Rocky Boy's). The Social Security Administration sent a team to the Blackfeet Reservation to assist people with disabilities to apply for SSDI, completing the application form on the spot. A follow-up visit was made by a team of physicians who then conducted physical examinations of applicants to verify and determine the level of disability. This outreach program reportedly resulted in about 70 people on the Blackfeet Reservation being approved for SSDI benefits (and eventually Medicare coverage). Tribal health staff was planning to go to the Fort Belknap SSDI outreach event with several Tribal members who they believed were eligible for SSDI to assist them with application forms.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Interviewees all stated they believe there is under-enrollment in Medicaid and SCHIP on the Reservation. One interviewee estimated that as much as 30 percent of people who are eligible for these programs are not enrolled.

#### **Barriers to Initial Enrollment**

The major barriers to enrollment identified by interviewees include:

- Enrollment paperwork is time-consuming, difficult to complete properly, and intimidating.
- Low literacy levels of some potentially eligible people make the complex enrollment paperwork an even greater barrier.
- Mail communications are also a problem, because of literacy issues. Most of the
  application and redetermination process is conducted through letters to applicants asking
  for additional information or copies of verification documents. A significant number of
  people do not understand these letters and either assume they have been turned down or
  fail to respond with the requested information.
- Insufficient assistance from County caseworkers is also a problem. Three caseworkers
  come to the Reservation for six hours every Wednesday, but this amount of time is
  inadequate to provide the level of assistance required by Tribal members. This is
  particularly the case since the County caseworkers are also responsible for assisting
  Tribal members to apply for Temporary Assistance for Needy Families (TANF) and food
  stamps.
- County caseworkers that are not adequately trained and knowledgeable about Medicaid and SCHIP program rules also are a barrier to enrollment. One example cited by interviewees included caseworkers requiring that grandparents raising grandchildren provide income verification even though this is not required of grandparents for children to be eligible for Medicaid and SCHIP. Interviewees said that these caseworkers were not new but had been in their positions for a sufficiently long time that they should have been aware of the eligibility rules. Interviewees raised the possibility that the caseworkers were deliberately raising barriers to avoid enrolling AI/ANs in Medicaid and SCHIP.

- Discrimination against AI/AN applicants by some County caseworkers was also thought to be a problem by some interviewees. They stated that when complaints were registered with the State about a specific caseworker who was particularly difficult and hostile toward Tribal members, the State temporarily removed him/her but then re-assigned him/her again to the Reservation.
- Montana has capped SCHIP enrollment and this means that children who are eligible for enrollment in SCHIP do not receive coverage or must wait a long time before they receive benefits.

### Barriers to Maintaining Enrollment

Redetermination of Medicaid and SCHIP often leads to termination of coverage when people do not understand the request for updated information or do not respond to the request on time. The State will not provide the Tribe with information on anniversary dates or on people who are undergoing redetermination, so Tribal benefits counselors are unaware and cannot assist people with redetermination.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Interviewees said that under-enrollment in Medicare Part B was a major problem. Barriers to enrollment in the Medicare program that were identified by interviewees included:

- Many elderly Tribal members believe that they can obtain all needed services from the Tribal clinic, so they have little incentive to enroll in or use Medicare benefits.
- The Part B premium is substantial relative to the very low incomes of many elderly people, so they elect not to participate in Part B.
- The process of applying for SSDI and associated Medicare coverage is extremely complex and burdensome and there is a perception that everyone is turned down after completing and submitting their application. As a result, people who are legitimately disabled and eligible for SSDI/Medicare often do not apply for this program.

### Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

Interviewees had a number of suggestions for strategies that might reduce barriers to enrollment and increase the number of people covered by Medicaid, SCHIP, and Medicare. These included:

- **Outstationed Medicaid worker**. The State should fund a full-time County caseworker that would work out of a permanent office on the Reservation.
- Fair Hearing Appeals process. The State should enforce the Fair Hearing Appeals process, to permit the removal or disciplining of any caseworker that appears to be discriminating against AI/AN people.

- Cultural training for County caseworkers. The State should provide cultural training and historical/legal background education to County caseworkers that are working with AI/ANs. This would possibly reduce discrimination, increase the accuracy of information on eligibility requirements, and improve the effective working relationships between caseworkers and Tribal members.
- **Training for State caseworkers**. The State should also require caseworkers to attend workshops on eligibility requirements and new provisions to ensure that all caseworkers are knowledgeable and accurate in the information they provide to applicants and that they make appropriate and fair eligibility determinations.
- Sharing of application and redetermination information with Tribal health staff. The State should share information on redetermination timing and processes underway with Tribal health staff, so that assistance can be provided to Tribal members to enable them to maintain enrollment in Medicaid and SCHIP.
- Electronic application and redetermination forms. The State should consider developing and offering electronic application and redetermination forms, as well as simplifying the application forms.
- One-on-one assistance with application processes. The State and Federal governments should provide for personal one-on-one assistance with application processes. Letters to communicate information are ineffective for many AI/ANs, but these people would likely be able to successfully complete the process if they had some in-person assistance.
- Improved communication from CMS. CMS should develop more understandable communications to Medicare beneficiaries or should send representatives out to the Tribes to talk to Medicare enrollees about issues related to Medicare coverage and benefits.
- **Tribal Medicaid progra**m. Interviewees also strongly suggested that the Federal government and CMS should create a Tribal Medicaid program—similar to Tribal TANF—that would permit Tribes to take over responsibility for outreach, enrollment, and management of the program. This would also permit Tribes to obtain the administrative funds associated with Medicaid and use those funds to develop targeted outreach and to provide enrollment assistance to Tribal members who are eligible for Medicaid.

#### FINDINGS: FORT BELKNAP RESERVATION

#### Overview

The Fort Belknap Reservation is home to the Assiniboine and Gros Ventre Tribes, which have an integrated Tribal governance system. The IHS provides services to approximately 4,700 people residing on or near the Fort Belknap Reservation.

The site visit to Fort Belknap was coordinated and scheduled by Julee King Kulbeck, Community Council Secretary-Treasurer. The project team met with Ethel Bear and Walter Horn, Tribal Council Members, and with the Tribal Health Director, Tribal TANF Director,

representatives from the elders programs, the CHR supervisor, Manager of the Personal Care Program, and the IHS Business Office Manager and Systems Health Specialist. In addition, the project team met with two of four Blaine County caseworkers assigned to work from a permanent office established at Fort Belknap. The project team also had an opportunity to talk with a number of elders during lunch at the Senior Citizens Center.

Tribal interviewees emphasized that the Fort Belknap Indian Reservation, as well as much of Montana, is classified as Frontier and, as a result, residents are more geographically isolated from services, travel distances to services require hours rather than minutes, and the harsh winters result in roads that become inaccessible. Interviewees stated that the population of the Fort Belknap Indian Reservation is 95 percent AI/AN and "suffers disproportionately from the lowest of health and poverty levels in Montana."

The IHS staff stressed that IHS makes significant efforts to identify people who are eligible for Medicaid, SCHIP, and Medicare. In addition, IHS policies require that patients apply for alternate insurance coverage and provide evidence of coverage or denial of eligibility prior to receiving authorization for IHS Contract Health Services.

The relationship between the Fort Belknap Reservation residents and Blaine County government staff appears to be more positive than this same relationship on the Rocky Boy's Reservation and on the Crow Reservation visited in Montana. The presence of a permanent office and assignment of Blaine County caseworker staff to assist Tribal members with enrollment and redetermination processes was evidence of this relationship and was perceived by both Tribal members and the caseworkers as a good mechanism for enrollment assistance. All four of the assigned caseworkers have been at the Fort Belknap location for 10 or more years.

Tribal members interviewed were also very enthusiastic about the Social Security Disability outreach project that scheduled for September 9, 2002, at Fort Belknap. Social Security Administration representatives from Havre and Great Falls would be at Fort Belknap on that date to take applications for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) for children and adults. It was anticipated that the Social Security Administration would follow-up this outreach by sending a team of physicians to Fort Belknap a few weeks later to conduct physical examinations and verify disability for individuals who submitted applications for SSDI. The Tribe was advertising the outreach program widely and expected a substantial number of people would be reached and assisted with application processes through this outreach effort.

The Tribe's elders program had also collaborated with the State of Montana and the University of Oklahoma to produce a video on "Medicare and Medicare Savings Programs," that featured Tribal members talking about and explaining the value of Medicare enrollment and what the Medicare Savings Programs cover.

Interviewees expressed considerable interest in the "American Indian/Alaska Native Eligibility and Enrollment in Medicaid, SCHIP, and Medicare Project" and thought it was a very useful undertaking. Several said that enrollment in these programs was particularly desirable because being covered by Medicaid, SCHIP, and/or Medicare gave people the choice of

obtaining care through the Fort Belknap IHS facility or going to providers outside the Reservation

## Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Interviewees generally believed that there is significant under-enrollment of Tribal members in Medicaid and SCHIP. They estimated that 40 to 50 percent of those eligible for programs such as Medicaid and TANF are not enrolled in these programs but did not have available or offer data to support these numbers.

### Barriers to Initial Enrollment

The barriers to enrollment that interviewees identified include:

- Some people believe strongly that health care is a treaty obligation of the Federal government and, therefore, they should not have to go through an application process in order to have health care benefits.
- The benefits to the whole Tribe increased funds for IHS, providing more resources for health care that result from Tribal members enrolling in Medicaid or SCHIP is not on the "radar screen" for most Tribal members.
- There is not sufficient staff available even with caseworkers assigned to the office on the Reservation to provide personal one-on-one assistance to all the people who need help with the application and redetermination process.
- The lack of staff also means that priorities must be set and, generally, the priority is to assist with Medicaid applications rather than SCHIP applications. This results in lower rates of enrollment in SCHIP.
- Many people do not have reliable, or any, transportation methods. Even with County caseworkers located at the Reservation offices, the lack of transportation makes it difficult for many people to obtain in-person assistance with the application process.
- The cap on SCHIP enrollment and the fact that approval of an SCHIP application does not result in immediate SCHIP enrollment is also a deterrent to enrollment.
- There is limited outreach and education to help people learn about Medicaid and SCHIP and, as a result, many people are not aware that they or their children may be eligible.
- When people apply for Medicaid or SCHIP and receive a letter that denies the application for technical reasons (e.g. additional documentation may be requested), they often believe this means they are turned down and they do not "follow up" to provide additional information.
- People who live in multiple-family households are often reluctant to apply for Medicaid or SCHIP because they fear the application process could result in scrutiny of all of the members of the household and, possibly, a loss of benefits to other household members.

- The Medicaid application process, particularly, is complex, confusing, and burdensome. People are deterred from applying by the difficulty of the forms.
- Interviewees thought there is a problem with the way the State evaluates AI/AN applicants' assets. Even though the State should not consider "Tribal income" and property, there is a perception that the State does consider these assets and uses them to deny eligibility for Medicaid/SCHIP.
- There also is fear on the part of many Tribal members that if they enroll in Medicaid, the State can recover the costs by confiscating their property after they die.

## Barriers to Maintaining Enrollment

Most interviewees said that the redetermination process for Medicaid and SCHIP was not particularly a problem for most people. However, several did comment that some people just put off filling out the forms until the last minute and, as a result, experience a break in enrollment.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

The major barriers raised by interviewees for Medicare and the Medicare Savings Program enrollment include:

- Elderly people tend to be more likely than younger people to feel that they should not have to go through any application process to get health care because of the treaty responsibilities of the Federal government.
- The Part B premium is high, relative to many elderly peoples' incomes, and so they turn down Part B coverage.
- There is a lack of awareness and understanding of the Medicare Savings Programs and their benefits. This is true both for elderly people and for some of the IHS and Tribal staff who could be available to assist in enrollment in these programs.

## Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

There was a wide-ranging and intense discussion of this issue during the interview because of the budget shortfall announced by the State and some drastic changes in Medicaid that were under consideration. During the discussion, the Executive Director of the Montana-Wyoming Tribal Leaders Council arrived at the Tribal headquarters and joined the meeting. He and other interviewees stated that the relationship between the Tribes in Montana and Montana State government was not good and, in fact, was deteriorating under the new governor.

Interviewees asked why the Federal government had designed a Medicaid program that ran through the State, when 100 percent reimbursement of Medicaid benefits provided to AI/ANs was paid by the Federal government. The State receives an administrative fee for each AI/AN person enrolled in Medicaid, but does little or nothing with that money to benefit AI/AN people.

Interviewees strongly suggested that the Federal government and CMS should create a Tribal Medicaid program – similar to Tribal TANF—that would permit Tribes to take over responsibility for outreach, enrollment, and management of the program. This would also permit Tribes to obtain the administrative funds associated with Medicaid and use those funds to develop targeted outreach and to provide enrollment assistance to Tribal members who are eligible for Medicaid.

Under the existing structures of the Medicaid and SCHIP programs, interviewees also had specific suggestions for changes that could reduce barriers and increase enrollment in these programs and in Medicare. These suggestions included:

- **Dedicated enrollment office located on Reservations**. The State should provide funding for a dedicated enrollment office on all Reservations, with staff available on a full-time basis. The funding should be sufficient to provide transportation services that would allow "door-to-door/face-to-face" application assistance.
- AI/AN caseworkers and cultural training for non-AI/AN caseworkers. It would also be helpful if the State would make greater efforts to recruit and hire caseworkers that are AI/AN and/or provide cultural training to caseworkers to help them better understand ways to work effectively with AI/AN people.
- State share enrollment information with Tribe. The State should share enrollment information and redetermination dates with the Tribe so that assistance can be provided to people who need help with the application and redetermination processes.
- Training for all staff who work with AI/ANs. The State and IHS should develop enhanced training programs for staff to ensure that all staff who work with Tribal members on enrollment issues are aware of and knowledgeable about all of the programs that are available, eligibility requirements for each, and the application processes.
- Increased outreach to AI/ANs on all programs. The State, CMS, and IHS should develop more outreach programs to increase awareness among Tribal members of Medicaid, SCHIP, and Medicare Savings Programs and eligibility criteria for these programs.
- Educational campaign directed at Tribal members on the benefits of public insurance programs. The Tribes and IHS should develop an educational campaign to help more people on the Reservation understand how enrollment in Medicaid, SCHIP, and Medicare can benefit everyone in the community by increasing resources to provide health care.

## FINDINGS: THE CROW RESERVATION

#### Overview

The Crow Reservation is 50 miles southeast of Billings and is contiguous to the Northern Cheyenne Reservation on the west and borders Wyoming on the south. Health services on the Crow Reservation are provided by the IHS, which offers both inpatient hospital services and

ambulatory services. Because of the proximity to Billings, users of the Crow Agency IHS facilities include a substantial number of AI/ANs who live in Billings, as well as those who live on or near the Reservation.

Manuela Mesteth, Tribal Health Director, coordinated site visit arrangements and scheduling. Interviews were conducted with Ms. Mesteth and with the Director of Social Services Programs, Tribal Health Planner, a member of the Tribal Health Board, and the IHS Benefits Counselor.

The Tribal Health Planner was relatively new to the position. She previously had been the coordinator for The Robert Wood Johnson Foundation Covering Kids Program for the Bighorn/Crow pilot project. She was, therefore, able to provide extensive information on SCHIP and on the strategies and results of the Covering Kids project on the Crow Reservation. The Crow Covering Kids (CCK) program provided four outreach workers on the Reservation and emphasized focused, personal assistance to help people complete SCHIP applications. In addition, the CCK staff conducted extensive informational campaigns and advertising of the SCHIP program on the Reservation. The CCK project enrolled about 180 children in SCHIP. However, CKK interviewees estimated that about 500 children who were eligible were not enrolled. In addition, the CCK staff identified "drop out" at annual redetermination as a major issue for SCHIP enrollment, estimating that about one in four children were dropped from SCHIP due to failure to submit required redetermination information.

The IHS is perceived by interviewees as being aggressive about encouraging and assisting Tribal members to enroll in Medicaid and SCHIP. There is a full-time benefits counselor at the Crow Agency IHS whose job is to identify people who are eligible for these programs and assist them with the enrollment process. <sup>200</sup> Interviewees did say that IHS does not generally require that patients show proof of application and enrollment (or denial of coverage) in Medicaid as a pre-requisite for approval of Contract Health Services.

Interviewees also noted that the Tribe does not have money to hire people to conduct outreach and assist Tribal members with application for Medicaid, SCHIP, and Medicare. The CCK project provided funds to hire four outreach and enrollment workers for several years, but when that funding ended, that assistance also ended.

## Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

There was general agreement among interviewees that there is significant underenrollment of Crow Tribal members in Medicaid and SCHIP.

#### Barriers to Initial Enrollment

The major barriers to enrollment mentioned by interviewees include:

<sup>&</sup>lt;sup>200</sup> This individual had been in the position for over 10 years and was retiring from IHS within a few months. Although he thought that IHS planned to find a replacement for him, there had not yet been an effort to identify a replacement and to train someone to take over his role.

- Some Tribal members believe strongly that health care is a treaty responsibility of the Federal government and that it should not be necessary to apply for coverage from other programs in order to obtain health services.
- Since the majority of Crow people speak the Crow language, their English facility may be limited particularly for older people. This makes the application process even more difficult to complete successfully.
- The Medicaid application form is very complex, confusing, and difficult to complete. Many people who begin the application process do not complete it because it is so complicated and burdensome.
- The Medicaid application form requires that the applicant submit documentation that may be difficult to obtain or non-existent such as birth and marriage certificates, divorce decrees, and, adoption/guardianship documentation. In addition, some applicants do not have access to copying machines.
- There is insufficient staff at IHS to provide the assistance needed by the large number of
  Tribal members who are eligible for Medicaid and SCHIP and the Tribe does not have
  resources to hire and train staff to provide this assistance. The single benefits counselor at
  IHS concentrates on helping people with Medicaid applications and with Medicare issues
  and does not have time to assist with SCHIP issues.
- Many Tribal members in particular are unaware of the availability of Medicaid benefits or do not believe they are likely to be eligible.
- There is a tendency among Tribal members to believe that a denial letter means that they should never apply again, even when the denial is simply because more information or documentation is needed to complete the application.
- Interviewees also reported racism and discrimination by County caseworkers as a barrier
  to enrollment. These experiences were known among community members and caused
  others to be reluctant to seek assistance from the caseworkers.
- Although the County has recently assigned a caseworker to visit the Reservation for one-half day a month to assist with applications, this amount of time is insufficient and provides very few people with assistance.
- Interviewees also said that they believe that the State frequently disallows Medicaid eligibility, based on the asset test, for Tribal members who own Federal Trust Lands on the Reservation. Trust lands are not supposed to be included as assets for considerations of Medicaid eligibility. When a Tribal member has an advocate and fights this, however, the State will exclude the trust land from the asset test. Most Tribal members do not have resources to fight the State on this issue, though, and do not pursue Medicaid eligibility when they are denied because of this issue.

### Barriers to Maintaining Enrollment

- Transportation is also a problem for many people who do not have reliable transportation to travel the 13 miles or more to Hardin (some people live up to 50 miles away) to obtain assistance with applications or redetermination forms.
- Retention of Tribal members enrolled in Medicaid and SCHIP is a problem, since the
  redetermination process requires considerable effort on the part of the applicant.
  According to the interviewees, the State does not share information about people who are
  in the annual redetermination process and, as a result, neither IHS nor the Tribe is able to
  offer assistance.

### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Interviewees had little information or understanding of Medicare and Medicare Savings Programs and were not able to identify barriers to enrollment, beyond the general ones that were cited as relevant to the Medicaid and SCHIP programs. Those include:

- Reluctance to apply for health programs because of the belief that the Federal government is responsible for providing health care for AI/ANs under treaties.
- Language barriers, particularly for older people whose first language is Crow.
- Lack of awareness of the benefits to themselves and to the community of obtaining Medicare reimbursement for services provided by IHS.

#### Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

Most interviewees had suggestions for strategies that might increase enrollment in these programs. Those suggestions include:

- More funding from the State, IHS, or CMS, to employ outreach workers, enrollment counselors, and advocates. The Tribe would like to hire these individuals, but does not have any funds to do so.
- More one-on-one enrollment assistance. In-person assistance is the most effective way to increase enrollment.
- Coordination between the State and IHS on application status. The State should consider coordinating and sharing information with IHS on the status of individual applications and the timing of redetermination processes, so that assistance could be provided to Tribal members who are in process.
- Education for caseworkers on Federal Trust Lands. The State should educate County caseworkers about the rules that govern Federal Trust Lands, so that Tribal members are not improperly denied enrollment based on the Medicaid asset test.

- Outstationed bilingual County caseworkers. The State should recruit and employ bilingual County eligibility caseworkers and place them on the Reservation on a permanent basis.
- Culturally appropriate outreach. Culturally appropriate outreach would be helpful to get the "message" about Medicaid and SCHIP out to people. These strategies might include translation of materials into the Crow language, holding health fairs at places that Crow members congregate, and providing information at pow-wows or other community gatherings.
- **Tribal support**. Tribal leadership explanation of the benefits to the whole community of Tribal members' enrollment in Medicaid, SCHIP, and Medicare would encourage people to enroll. The Tribe should also communicate that enrollment in these programs gives Tribal members more choices between IHS and private health providers, which could be an effective message because of concerns about quality of care and limited funds at IHS.
- Outreach campaigns. The State, IHS, and CMS should develop targeted outreach campaigns using media that are most likely to be effective on this Reservation. Interviewees suggested that posters and newsletters that incorporate pictures and stories about local community members would likely be more effective that television advertisements or mail campaigns.
- Training for Community Health Representatives. The Tribe should consider providing training to Tribal Community Health Representatives on Medicaid, SCHIP, and Medicare and encourage them to talk with people about these programs and to provide assistance with application and redetermination processes.

### FINDINGS: INDIAN HEALTH BOARD OF BILLINGS

#### Overview

The Indian Health Board of Billings (IHBB) provides limited services, focusing primarily on mental health and substance abuse services. Funding for the services it provides comes primarily from an Indian Health Service grant and from third-party reimbursements. Staff includes one psychologist, four substance abuse counselors, and one mental health assistant. In addition, three physicians and one nurse practitioner provide health services to patients for a very limited number of hours each week. Many patients who require physical health services are referred to local community health centers or to the IHS facility at Crow Agency. The clinic provides transportation for clients who are referred to Crow Agency.

The IHBB employs one benefits counselor who provides application assistance to Tribal members. The benefits counselor estimates that about 25 to 30 percent of clients seen at IHBB have Medicaid coverage and that the majority of elderly people seen at the clinic have both Medicare Part A and Part B. The benefits counselor was not aware of the SCHIP program and did not have any information on the number of children who were covered or barriers to enrollment.

### Current Enrollment and Barriers to Enrollment in Medicaid, SCHIP, and Medicare

#### Barriers to Initial Enrollment

- The IHBB interviewees said that the greatest barrier to enrollment in Medicaid is the difficult paperwork and documentation that must be completed. Many AI/AN people who start the process give up rather than try to complete the paperwork.
- The other main reason that Tribal members do not enroll in third-party insurance programs is that IHBB and IHS services are available to them at no cost, so they see no reason to enroll.

## Barriers to Maintaining Enrollment

• Interviewees did not cite any barriers to maintaining enrollment

### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Interviewees did not cite any barriers to enrollment in the Medicare and Medicare Savings Programs.

## Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

Interviewees suggested several strategies that might be effective to increase enrollment in Medicaid, SCHIP, and Medicare. These include:

- Outreach and education on application processes. More outreach and education on "how to apply" would be helpful, if the State or Federal government were to provide funds to develop campaigns and hire outreach workers.
- Funding for outreach and education staff. More funding for staff to educate people about these programs and to provide in-person assistance (at the clinic or in peoples' homes) with the application process would be helpful.
- Education about benefits of enrolling in programs. Education about how enrollment in these programs could lead to increased services and capacities at IHBB could encourage people to apply.

### **DISCUSSION**

The State of Montana was in a budget crisis at the time of our site visits to Montana, dominating our discussions with most of the Tribal organizations visited. The State was considering cutbacks in the Medicaid program that would have affected the number of people eligible for Medicaid and would have reduced benefits provided under the program. The Montana SCHIP program already has a cap on enrollment and the State was considering lowering that cap even further. Representatives from the Tribes visited and from the Tribal Leaders Council were concerned that these cutbacks would have negative impacts on AI/AN people in Montana. These interviewees questioned why the State is given the responsibility for

determining eligibility and enrollment of AI/AN people in Medicaid, when the Federal government pays 100 percent of the costs of Medicaid services provided to AI/ANs by the IHS. Several interviewees strongly stated that the Federal government should permit the development of a Tribal Medicaid program, allowing Tribes to receive the administrative Medicaid funds and to use these funds to conduct outreach and provide enrollment assistance to Tribal members. A Tribal Medicaid program would also encourage Tribal members to enroll in these programs because it would be "their" program, rather than perceived as a State program. In addition, concerns about discrimination against AI/AN people by eligibility workers would likely be reduced if Medicaid were a Tribally managed program.

There was general consensus among all interviewees that under-enrollment in Medicaid, SCHIP, and Medicare was a serious issue for AI/AN people in Montana, <sup>201</sup> due to lack of data on the number of AI/AN people who are eligible and on the number of AI/AN people who are currently enrolled. There were, however, differences among the Tribes/Reservations visited in the role of the Tribal health departments and IHS in outreach and enrollment activities. While the IHS facility at Fort Belknap requires people to apply for Medicaid and other alternative coverage in order to receive authorization for Contract Health Services, the Crow Agency Service Unit and the Tribally managed health facility at the Rocky Boy's Reservation do not require such proof. The Chippewa-Cree Tribe and the Fort Belknap Tribal Health Department both provide a limited amount of outreach and assistance to help people apply for Medicaid, SCHIP, and Medicare; however, the Crow Tribe does not provide this assistance and cited lack of funds as the reason it is unable to provide this service.

Across all of the Tribes and urban facilities visited, there was agreement that more effort should be made – by CMS, the State, IHS, and by the Tribes – to provide outreach, education, and enrollment assistance and that this assistance would be most effective if it were designed to be culturally-appropriate and if AI/ANs could be recruited to conduct the outreach and provide assistance.

<sup>&</sup>lt;sup>201</sup> One exception to that consensus was the view of the County caseworkers at Fort Belknap, who believed that a higher proportion of eligible AI/AN people were enrolled in Medicaid than non-AI/AN people.

# APPENDIX VI.A: MONTANA SITE VISIT CONTACT LIST

# **Billings Area Organizations**

Name	Title	Address	Phone	Email
Sula St. Mark	Outreach worker	Indian Health Board of Billings 1127 Alderson Ave. Billings, MT 59102	406-245-7372 or 7318	ihbb@mcn.net
Mark Sollars	Substance Abuse Counselor	Indian Health Board of Billings 1127 Alderson Ave. Billings, MT 59102	406-245-7318	Not Available
Nicole Leahy	Health Specialist	Indian Health Board of Billings 1127 Alderson Ave. Billings, MT 59102	406-245-7318	Not Available
Charles Lewis	Acting Associate Director	Billings Area IHS 2900 4 <sup>th</sup> Ave. N. Billings, MT 59101	800-277-5997	Not Available
Gordon Belcourt	Executive Dir., MT/WY Tribal Chairman's Health Board	MT/WY Tribal Leaders Council 207 N. Broadway Billings, MT 59102	406-252-2250	belcourt@wtp.net
Garfield Little Light	Not Available	Billings Area IHS 2900 4 <sup>th</sup> Ave. N. Billings, MT 59101	406-247-7106	Garfield.Littlelight@mail.ihs.gov
DJ Lott	Executive Director	Great Falls Indian Family Health Clinic 1220 Central Ave. Great Falls, MT 59401	406-268-1510	d_i_lott@hotmail.com

# Fort Belknap

Name	Title	Address	Phone	Email
Richard King	Tribal Health Director	Fort Belknap Route 1, Box 66 Harlem, MT 59526	406-353-2205	Not Available
Gail Show	Administrative Assistant	Fort Belknap Route 1, Box 66 Harlem, MT 59526	406-353-2205	Not Available
Nadine Sullivan	Personal Care Program Manager	Fort Belknap Route 1, Box 66 Harlem, MT 59526	406-353-2205	Not Available
Delina Cuts The Rope	477 Director/TANF Manager	Fort Belknap Route 1, Box 66 Harlem, MT 59526	406-353-2205	Not Available
Carla King	TANF Fiscal	Fort Belknap	406-353-2205	kyramonai@yahoo.com

Name	Title	Address	Phone	Email
	Manager	Route 1, Box 66 Harlem, MT 59526		
Joyce Castillo	Title VI – Elders	Fort Belknap Route 1, Box 66 Harlem, MT 59526	406-353-8417	Not Available
Tracy R. King	CHR Supervisor Fort Belknap Route 1, Box 66 Harlem, MT 59526		406-353-2205	tracyrose10@hotmail.com
Mary Ellen Bird In Ground	IHS Systems Health Specialist	Fort Belknap Route 1, Box 66 Harlem, MT 59526	406-353-3195	Not Available
Judy Thomas	IHS Business Office Manager	Fort Belknap Route 1, Box 66 Harlem, MT 59526	406-353-3154	Not Available
Julie King Kulbeck	Community Council Sec / Treasurer	Fort Belknap Route 1, Box 66 Harlem, MT 59526	406-353-2205	juleekk@yahoo.com
Ethel Bear	Community Council Member	Fort Belknap Route 1, Box 66 Harlem, MT 59526	406-353-8425	Not Available
Walter Horn	Community Council Member	Fort Belknap Route 1, Box 66 Harlem, MT 59526	406-353-8436	Not Available
Kathi Molyneaux	Blaine County Case Worker	100 Chippewa St W, Harlem, Mt 59526	406-353-4269	Not Available
Charlotte Brummer	Blaine County Case Worker	100 Chippewa St W, Harlem, Mt 59526	406-353-4269	Not Available

# **Crow Agency**

Name	Title	Address	Phone	Email Address
Dolly Not Afraid Howe	Tribal Health Planner	P.O. Box 159 Crow Agency, MT 59022	406-638-2601	Not Available
Elroy Nomee	Tribal Health Board member	P.O. Box 159 Crow Agency, MT 59022	406-638-2601	Not Available
Curtis Brien	IHS Community Health Director	P.O. Box 159 Crow Agency, MT 406-638-2601 59022		Not Available
Charles Wilson	IHS Benefits Counselor	P.O. Box 159 Crow Agency, MT 59022	406-638-2626	charles.wilson@mail.ihs.ne t.gov
Rene Frank	Director, Health and Human Services	P.O. Box 159 Crow Agency, MT 59022	406-638-3811	Not Available
Manuella Mesteth	Tribal Health Director	P.O. Box 159 Crow Agency, MT 59022	406-638-2626	Not Available

# **State Agency Officials**

Name	Title	Address	Phone	Email
Mary Noel	CHIP Director	PO Box 202951 Helena, MT 59620	406-444-6992	manoel@State.mt.us
Kathe Quittenton	Family Medicaid Specialist	PO Box 202952 Helena, MT 59620	406-444-9022	kquittenton@State.mt.us
Hank Hudson	Administrator, Human and County Services Division	PO Box 202952 Helena, MT 59620	406-444-5902	hhudson@State.mt.us

# **Rocky Boy's Reservation**

Name	Title	Address	Phone	Email
Ivy Parker	Assistant CEO/ CHR and Facility Accreditation	Rocky Boy Health Center RR1 Box 664 Box Elder, MT 59521	Not Available	Not Available
Renita Watson	Alternate Resource Benefits Coordinator	Rocky Boy Health Center RR1 Box 664 Box Elder, MT 59521	406-395-4486, ext 229	Renita_Watson@hotmail.com
Loni Whitford	Medicaid/CHIP Outreach Worker	Rocky Boy Health Center RR1 Box 664 Box Elder, MT 59521	Not Available	Not Available
Kevin J. Barsotti	Box Elder Schools Counselor	Box Elder Schools PO Box 205 Box Elder, MT 59521	406-352-4195	Not Available
Linda Nault	CHS Assistant/ Travel manager	Rocky Boy Health Center RR1 Box 664 Box Elder, MT 59521	Not Available	Not Available
Judy Parker	CHR	Rocky Boy Health Center RR1 Box 664 Box Elder, MT 59521	Not Available	Not Available
Karen Morsette	Not Available	Rocky Boy Health Center RR1 Box 664 Box Elder, MT 59521	Not Available	Not Available
Charlene Big Knife	Billing Clerk	Rocky Boy Health Center RR1 Box 664 Box Elder, MT 59521	406-395-4486	billing@rockyboy.org
Marilyn Sutherland	Vocational Rehab Assistant/ Disabilities	Rocky Boy Health Center RR1 Box 664 Box Elder, MT 59521	406-395-4733	Not Available

Name	Title	Address	Phone	Email
Jonathan Windy Boy	Tribal Council Member	Chippewa Cree Tribal Council RR1 Box 544 Box Elder, MT 59521	406-395-4282	jonathan@rockyboy.org
Alvin Windy Boy, Sr.	Tribal Chairman	Chippewa Cree Tribal Council RR1 Box 544 Box Elder, MT 59521	406-395-4282	Not Available
Bruce Sunchild	Vice Chair of Tribal Council	Rocky Boy Health Center RR1 Box 664 Box Elder, MT 59521	406-395-4486	Not Available

# APPENDIX VI.B: ALTERNATE RESOURCES HISTORICAL REPORT

# FORT BELKNAP HISTORICAL DATA REVIEW

Fiscal Year	I.H.S. Budget Amount	User Pop	Total Visits	Medicare Visits	Medicaid Visits		Medicare Collections	Medicaid Collections	PI Collections	PI % Reimbursed
1991	\$6,400.9	4,319	34,933	3,911	7,649	4,949	\$188,582	\$472,216	\$9,980	no data
1992	\$6,120.2	4,336	36,480	4,193	8,221	5,853	349,004	588,528	69,319	40.8%
1993	\$6,353.4	4,314	44,249	4,339	10,821	7,354	268,962	520,323	139,326	34.6%
1994	\$6,560.2	4,588	44,234	4,452	10,782	7,212	304,371	868,336	137,425	43.8%
1995	\$7,769.6	4,637	46,802	5,066	11,802	7,263	410,755	574,560	199,721	48.2%
1996	\$6,717.9	4,755	52,010	6,078	13,420	7,763	404,357	1,713,830	309,978	50.6%
1997	\$9,533.4	4,863	50,358	6,084	13,424	6,462	573,924	1,167,244	330,685	46.2%
1998	\$9,487.0	5,572	50,878	6,918	13,861	7,503	237,456	1,325,070	183,110	45.9%
1999	\$10,198.2		55,493	7,929	16,163	7,900	366,403	1,885,186	253,058	49.8%
2000	\$10,678.7		60,233	8,711	16,696	8,412	696,824	1,548,008	341,047	43.8%
2001	\$10,809.7		67,177	10,344	18,524	9,858	539,645	1,812,096	452,634	40.7%

FY 2001 data as of 11-01-01.

The data was compiled from the RPMS PCC reports, third party billing reports and finance.

The budget also includes Tribal, M&I, environmental health, facilities, and quarters.

## **CROW AGENCY HISTORICAL DATA REVIEW**

Fiscal Year	I.H.S Budget Amount		Total Visits	Medicare Visits	Medicaid Visits		Medicare Collections	Medicaid Collections	PI Collections	PI % Reimbursed
1991	11,584.7	9,497	74,159	5,238	13,037	3,867	\$411,648	\$957,232	\$44,548	45.0%
1992	11,429.5	9,749	78,881	5,761	15,602	6,953	594,295	1,172,943	172,085	35.2%
1993	12,394.5	9,794	89,952	6,400	18,474	9,738	475,658	1,085,568	326,057	34.2%
1994	12,781.4	10,073	90,116	7,424	19,114	11,284	658,184	1,592,492	370,869	39.2%
1995	16,781.5	10,254	92,159	8,129	19,627	12,605	557,123	1,203,892	437,821	50.3%
1996	17,643.7	10,532	112,581	9,832	24,547	17,053	752,693	3,040,153	904,561	42.8%
1997	17,648.5	10,860	116,630	11,340	22,875	17,969	994,302	2,473,877	1,348,711	46.9%
1998	18,431.9	12,422	120,772	11,871	22,796	19,076	703,695	2,740,889	1,370,801	51.3%
1999	19,455.2		129,107	14,171	23,931	19,630	613,094	3,250,974	1,148,796	45.9%
2000	20,565.7		131,598	14,547	24,165	20,667	1,173,017	3,231,453	1,259,041	44.9%
2001	20,945.8		130,371	15,220	24,258	20,587	1,089,285	3,194,476	1,164,216	43.8%

FY 2001 data as of 11-01-01.

The data was compiled from the RPMS PCC reports, Third Party Billing reports and Finance.

The budget also includes Tribal, M&I, environmental health, facilities, and quarters.

## CHAPTER VII. NORTH DAKOTA

#### **BACKGROUND**

#### Overview

This Case Study Report presents background information and findings from a four-day site visit to North Dakota conducted from November 12 through November 15, 2002. The site visit team included Kathryn Langwell and Tom Dunn of Project HOPE and Frank Ryan, J.D., a consultant to the project. Conducting interviews with individuals and groups in each location, the team visited the Turtle Mountain Reservation and the Trenton Indian Service Area, their respective health services facilities, and State agency staff and others at the North Dakota State Capitol Building, located in Bismarck, North Dakota. The State of North Dakota does not have an Urban Indian Health Center; however, a representative from Fargo Community Health Center participated in the interviews at the State Capitol. The process for selecting the sites visited and description of the sites is provided in the following section.

An earlier version of this Draft Case Study Report was reviewed by the Centers for Medicare & Medicaid (CMS) Project Officer and by CMS staff, for accuracy and clarity. Subsequently, a Draft Case Study Report was sent to each of the North Dakota organizations that participated in the site visit, with a request that the draft be reviewed for accuracy and that comments and additions be incorporated into the Case Study Report. Despite follow-up contacts with these organizations, no comments and corrections were received from staff of North Dakota Tribes that were visited. North Dakota State Government staff, however, did review the draft and provided comments on specific aspects of the Report. These comments and corrections are presented in Appendix VII.B to this Case Study Report.

The comments and recommendations contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or the feasibility of the recommendations. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services, the Indian Health Service (IHS), or the State.

# North Dakota AI/AN Population and Location<sup>202</sup>

The State of North Dakota has five Reservations and one Indian Service Area, and several Federally Recognized Tribes, including the Standing Rock Sioux, Lake Traverse (Sisseton-Wahpeton) Sioux, Spirit Lake (Sisseton-Wahpeton) Sioux, Chippewa (Turtle Mountain Band and Trenton Indian Service Area), and the Arikaras, Hidatsas, and Mandans<sup>203</sup> (Fort Berthold Reservation). All these Tribes fall under the jurisdictional oversight and administration of the Aberdeen Area Office of the Indian Health Service (IHS). The 2000 Census reports that

http://www.ihs.gov/FacilitiesServices/AreaOffices/Aberdeen/aberdeen-history-Tribal-movement.asp, accessed March 7, 2003.

<sup>&</sup>lt;sup>203</sup> a.k.a. "Three Affiliated Tribes"

North Dakota<sup>204</sup> has a total population of 642,200, with an AI/AN population of 35,228 (5.5 percent). Table 1, below, provides data on each North Dakota Tribe's population.

**Table 1. Characteristics of Reservations in North Dakota** 

Tribe	Reservation	Tribally Enrolled Population	Total Reservation Population	AI/AN as a Percent of Total Reservation Population
Mandan, Hidatsa, & Arikara Nation (Three Affiliated Tribes)	Fort Berthold	8,700	5,915	67.4%
Spirit Lake Sioux	Spirit Lake	4,300	4,435	74.8%
Standing Rock Sioux Tribe	Standing Rock	13,000	4,044	84.6%
Turtle Mountain Band of Chippewa	Turtle Mountain	28,000	8,307	96.4%
Turtle Mountain Band of Chippewa	Trenton Indian Service Area	1,800 - IHS User Population	na	na
Sisseton-Wahpeton Sioux Tribe	Lake Traverse	10,200	na	Na

Note: http://www.health.State.nd.us/ndiac/statistics.htm, accessed March 10, 2003.

Note: Enrolled population for each Tribe is from 2002 BIA data.

Note: The Trenton Indian Service Area is not a Reservation, but rather a large geographic area in North Dakota and Montana where non-contiguous land allotments were given to individual AI/ANs.

Note: The majority of the Standing Rock and Lake Traverse Reservations lies within the borders of South Dakota. Source: U.S. Census Bureau, Census 2000 Summary File 1, various Matrices. http://factfinder.census.gov/bf/\_lang=en\_vt\_name=DEC\_2000\_SF1\_U\_DP1\_geo\_id=04000US38.html, accessed March 10, 2003.

Table 2 provides data on the number and proportion of the population that is AI/AN in each of the primary counties where Reservations are located in North Dakota, ranging from 74.5 percent in the primary County for Turtle Mountain, to 2.1 percent in the Lake Traverse primary County. The median age on the Standing Rock and Turtle Mountain Reservations is 23.9 years and 28.9 years, respectively, relatively younger than the North Dakota population, which has a median age of 36.2 years (Table 2).

Source: U.S. Census Bureau, Profile of General Demographic Characteristics: 2000. http://factfinder.census.gov/bf/\_lang=en\_vt\_name=DEC\_2000\_SF1\_U\_DP1\_geo\_id=04000US38.html, accessed March 10, 2003.

Table 2 Percent AI/AN Population and Median Age in Primary Reservation Counties in North Dakota 205

	Spirit Lake	Lake Traverse	Standing Rock	Ft. Berthold	Turtle Mountain	North Dakota	US
Percent AI/AN population	48.8%	2.1%	85.3%	31.0%	74.5%	5.5%	1.5%
Median age	31.4	35.4	23.9	39.6	28.9	36.2	35.3

Source: U.S. Census Bureau, Census 2000 Redistricting Data (Public Law 94-171) Summary File, Matrices PL1, PL2, PL3, and PL4. Note: Some Reservations extend over multiple counties. The data in this Table is drawn from the Reservation County that has the largest number of persons who reported AI/AN race, alone or in combination with one or more other races, on the 2000 Census. The Census Bureau had not vet released public use files providing data on Reservation populations, at the time this report was prepared, and it was not possible to construct population profiles for individual Reservations. It is anticipated that 2000 Census data on Reservation areas will be released in December 2003.

The overall number of South Dakota families with incomes below the Federal Poverty Level (FPL) has decreased since 1989. An estimated 99,871<sup>206</sup> South Dakota families had incomes below the FPL in 2000, compared to 106,305 in 1989,<sup>207</sup> constituting a 2.6 percentage point decrease in the proportion of families with incomes below the FPL over that period. During that same reporting period, the median household income in South Dakota grew from \$22,503 (1989)<sup>208</sup> to \$35,282 (1999).<sup>209</sup> However, the incomes of most AI/ANs residing on Reservations in South Dakota are substantially lower than the South Dakota average. The three poorest Reservations in the State reported an average per capita income of \$6,321 in 1999, which is 64 percent lower than the rest of South Dakota (\$17,562), and 71 percent lower than the US as a whole (\$21,587). 210,211 (see Table 3.)

Source: 2000 U.S. Census Bureau. Census Summary File 1, Matrices. http://factfinder.census.gov/bf/ lang=en vt name=DEC 2000 SF1 U DP1 geo id=04000US38.html, accessed March 10, 2003.

<sup>&</sup>lt;sup>206</sup> U.S. Census Bureau, State and County Quick Facts. http://quickfacts.census.gov/qfd/States/46000.html, accessed February 18, 2003 <sup>207</sup> U.S. Census Bureau, U.S. Bureau of the Census, 1990 Census of Population and Housing, Summary Tape File 3

<sup>(</sup>Sample Data): 1989 http://factfinder.census.gov/servlet/QTTable? ts=63649482510, accessed February 18, 2003

U.S. Census Bureau, County Estimates for Median Household Income for South Dakota: Census 1989. http://www.census.gov/hhes/www/saipe/stctv/ccn 46.htm.

U.S. Census Bureau, State and County Quick Facts, http://quickfacts.census.gov/qfd/States/46000.html.

http://factfinder.census.gov/bf/ lang=en\_vt\_name=DEC\_2000\_SF3\_U\_DP3\_geo\_id=01000US.html, accessed February 17, 2003.

U.S. Bureau. Census 2000 Summary matrices, http://factfinder.census.gov/bf/ lang=en vt name=DEC 2000 SF3 U DP3 geo id=01000US.html, accessed February 17, 2003.

Table 3. Economic Characteristics in Primary Reservation Counties in North Dakota, 1999

			J				
	Crow Creek	Pine Ridge	Rosebu d	Cheyenne River	Lower Brule	South Dakota	US
1999 Per Capita Income	\$5,213	\$6,286	\$7,714	\$7,463	\$13,862	\$17,562	\$21,587
	Pe	ercent Belov	v Federal	Poverty Lev	vel, 1999		
All Families (%)	55.7	45.1	44.0	45.2	19.4	9.3	9.2
FamiliesWith Children Under 18 Years (%)	61.2	51.8	49.9	55.0	26.9	13.9	13.6
Individuals aged 18-64 (%)	53.5	45.4	41.2	42.1	19.5	11.7	10.9
Individuals aged 65 and older (%)	50.4	36.0	33.5	27.2	12.9	11.1	9.9

**Table 3. Economic Characteristics in Primary Reservation Counties in North Dakota, 1999** (continued)

(continued)							
	Crow Creek	Pine Ridge	Rosebu d	Cheyenne River	Lower Brule	South Dakota	US
1999 Per Capita Income	\$5,213	\$6,286	\$7,714	\$7,463	\$13,862	\$17,562	\$21,587
	Pe	ercent Belov	v Federal	Poverty Lev	vel, 1999		
All Families (%)	55.7	45.1	44.0	45.2	19.4	9.3	9.2
FamiliesWith Children Under 18 Years (%)	61.2	51.8	49.9	55.0	26.9	13.9	13.6
Individuals aged 18-64 (%)	53.5	45.4	41.2	42.1	19.5	11.7	10.9
Individuals aged 65 and older (%)	50.4	36.0	33.5	27.2	12.9	11.1	9.9

Source: U.S. Census Bureau, Census 2000 Redistricting Data (Public Law 94-171) Summary File, Matrices PL1, PL2, PL3, and PL4.Note: Some Reservations extend over multiple counties. The data in this Table are drawn from the Reservation County that has the largest number of persons who reported AI/AN race, alone or in combination with one or more other races, on the 2000 Census. The Census Bureau had not yet released public use files providing data on Reservation populations, at the time this report was prepared, and it was not possible to construct population profiles for individual Reservations. It is anticipated that 2000 Census data on Reservation areas will be released in December 2003.

Note: Poverty data in this table isolates AI/AN statistics from the rest of the Reservation County's population.

The poor health status of the American Indian and Alaska Native population, relative to the U.S. population as a whole, has been well documented. In addition, there are also great disparities in health status among American Indian and Alaska Native populations. The IHS Aberdeen Area (of which South Dakota is a constituent) American Indian population exhibits much poorer health status than the average for the rest of the nation's AI/AN population. Infant

<sup>&</sup>lt;sup>212</sup> Source: T. Young, "Recent Health Trends in the Native American Population," in *Changing Numbers, Changing Needs: American Indian Demography and Public Health*, National Research Council, pp53-75; US Department of Health and Human Services, Trends in Indian Health, 1997, Indian Health Service.

<sup>&</sup>lt;sup>213</sup> US DHHS, Regional Differences in Indian Health, 1997, Indian Health Service.

mortality rates in the Aberdeen Area are 85 percent higher than the U.S. All Races rates; death rates from cancer are 30 percent higher than the U.S. All Races rate, and the tuberculosis rate is the highest among all IHS regions. Life expectancy of the Indian population in the Aberdeen Area is also substantially lower. American Indian males in the Aberdeen Area had a life expectancy of 61 years in 1994-96, compared with 73 years for all U.S. males and 70 years for all AI/AN males.

# AI/AN Health Services in North Dakota<sup>214</sup>

The IHS manages all health facilities in North Dakota, with the exception of the Tribally operated health clinic that serves the Trenton Indian Service Area. A brief description of each health facility that serves Indian people in North Dakota is provided in this section.

Turtle Mountain Reservation: The Quentin N. Burdick Memorial Health Care facility has 29 beds and 11 physicians (19 of the beds are for Medical/Surgical patients, 6 beds for Obstetrics, 4 for Pediatrics, and 6 bassinets for newborns). In addition to inpatient care, the hospital provides general surgery, <sup>215</sup> ENT surgery, obstetrics, optometry, audiology, and has the only CT scan equipment in the area. The outpatient department offers basic services and specialty clinics with contracted specialists.<sup>216</sup> The dental program consists of a comprehensive clinic at the hospital and a two-chair dental satellite station at Dunseith. The facility also includes a mental health department, consisting of one full-time consulting clinical psychologist, one staff psychologist, a psychiatric nurse, and a psychiatrist. The new clinic/hospital can employ 215 people.

Fort Berthold Reservation: The Minne-Tohe Health Center serves the members of the Three Affiliated Tribes on the Fort Berthold Reservation. The two-physician center is four miles west of New Town, North Dakota. The center is an outpatient facility with specialty and dental clinics. Inpatient care is provided by contract with local hospitals including the Minot hospital. The Tribes also have a contract to operate two health stations, one in Mandaree and one in White Shield, which are staffed by a physician's assistant from Fort Berthold. The Tribes also operate a Health Care Satellite Clinic in Twin Buttes that is staffed by a nurse practitioner

Fort Totten Reservation: The Spirit Lake Nation is served by a three-physician ambulatory care facility. Complex outpatient services and inpatient care are referred to a contract facility. Fort Totten operates a dental clinic and a diabetes program with comprehensive screening, education, and treatment.

today.asp, accessed March 7, 2003.

<sup>&</sup>lt;sup>214</sup>http://www.ihs.gov/FacilitiesServices/AreaOffices/Aberdeen/turtlemountain/ab-tm-healthcare-history.asp, accessed March 7, 2003; http://www.ihs.gov/FacilitiesServices/AreaOffices/Aberdeen/aberdeen-Tribes-facilities-

A staff surgeon oversees the Surgery program, including a contract with the University of North Dakota School of Medicine in Grand Forks. The University's School of Medicine sends surgery residents every other month for a four-week rotation.

<sup>&</sup>lt;sup>216</sup> The facility provides contract care for patients through specialists in Rugby, Grand Forks, Minot, Mayo Clinic, University of Minnesota, and other facilities. Patients have access to air ambulance services out of Minot or charter flights out of the Rolla airport, located seven miles east of the Reservation.

Lake Traverse Reservation: In Sisseton, South Dakota, the Sisseton Service Unit operates an 18-bed hospital with outpatient and dental clinics, staffed by 5 physicians. The hospital also boasts a well-developed referral system. The programs administered by the Sisseton-Wahpeton Tribe include an alcohol treatment program, community health, family planning, maternal and child health services.

Standing Rock Reservation: The 16-bed hospital at Fort Yates, North Dakota, has a staff of four physicians and a dialysis unit. Dental care is provided in the main clinic at the hospital by two dental officers and in a mobile clinic by one dental officer. An outpatient health center at McLaughlin has one staff physician. There are also health stations at Cannonball, Bullhead, and Wakpala. The health stations provide minimal outpatient care and are staffed by a physician's assistant, a public health nurse, and a community health representative. A physician from the Fort Yates hospital visits these health stations at least once a week.

Trenton Indian Service Area: The Trenton Indian Service Area operates a health clinic under a P.L. 93-638 self-determination contract with the IHS. The Tribal government contracts with a medical group practice in nearby Williston, North Dakota to provide primary care and specialty care services to Tribal members. Hospital services are provided by the community hospital in Williston.

#### **Overview of North Dakota State Government**

The North Dakota Indian Affairs Commission (NDIAC) consists of the Governor, four members appointed by the Governor from the State at large, three of whom must be of American Indian descent, enrolled members of a Tribe, current voting residents of the State of North Dakota, and the chairpersons of the Standing Rock, Fort Berthold, Fort Totten, and Turtle Mountain Indian Reservations. The Governor is the chairperson of the Commission. The Commission meets quarterly or as otherwise agreed.<sup>217</sup>

The Commission is the liaison between the Executive Branch and the Tribes in North Dakota. Duties include mediation service with the Tribes and State and interacting with other State agencies regarding proper protocol in working with American Indian people and Tribal governments. The goals of the Commission are to:

- Increase and maximize educational opportunities for American Indians in North Dakota.
- Increase the economic self-sufficiency of American Indians in North Dakota and maximize Indian economic development initiatives.
- Achieve parity in employment for American Indians of North Dakota.
- Improve the health status of American Indians in North Dakota.
- Increase the public awareness of American Indians.
- Provide for the State and/or Federal recognition of North Dakota Indian Tribes.

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<sup>&</sup>lt;sup>217</sup> http://www.health.State.nd.us/ndiac/, accessed March 10, 2003.

• Promote recognition of and the right of American Indians to pursue cultural and religious traditions considered by them to be sacred and meaningful and to promote public understanding and appreciation of Indian culture.

# North Dakota State Medicaid Program<sup>218</sup>

Initially authorized in 1966, North Dakota's Medicaid program was designed to strengthen and extend the provision of medical care and services to people who lack the resources to meet such costs. Ancillary to this goal, corrective, preventive, and rehabilitative medical services are provided with the objective of retaining or attaining capability for independence, self-care, and support. These services are extended to elderly, blind, or disabled individuals as well as to caretaker relatives and children to the age of 21 years. Federal, State, and County governments share the fiscal burden for Medicaid. For Federal fiscal year ending September 30, 2003, the funding for Medicaid is 68.4 percent (Federal) and 31.6 percent (State). The Medical Services Division operates on a total (2001-03) biennial budget of \$667,334,990.

The total number of persons enrolled in North Dakota Medicaid, in April 2003, was 54,155 –an increase of 10 percent from the same month in 2002 and 23 percent higher than the average enrollment during the twelve months ending July of 2001. <sup>219</sup> Total payments in April 2003 for all Medicaid age categories and services provided was \$38,853,072, compared to \$41,144,996 in April 2002.

North Dakota's Medicaid eligibility determination process is decentralized and conducted at the County level. Table 4 lists income levels for each of the various eligibility categories. The following is a general outline of Medicaid Program eligibility requirements (as of January 2003):

- <u>Medicaid Asset Limits</u>: Aged, Blind or Disabled: \$3,000 for a one-person household, \$6,000 for a two-person household, plus \$25 for each additional person in the household. Nursing Home Services: Institutionalized person: \$3,000; Spouse in the Community: \$90,660 (which increases every January).
- Assets that are not counted include: Family home; one automobile; burial plans (with limits); self-employment property, tools, equipment and livestock; non-saleable property; personal effects and clothing; household goods and furniture; Indian trust and restricted lands; and per capita and judgment funds. Other miscellaneous assets may be excluded depending on the specific Medicaid eligibility category. Effective January 1, 2002, the Medicaid program's children and family coverage group does not have an asset limit.
- <u>Income</u>: Depending on a family's net income, individuals may be eligible for full Medicaid benefits or may be responsible for a portion of their medical bills, which is called their "recipient liability." The amount of recipient liability is determined based on income level of the enrolled person. Medicaid looks at a family's total countable income

<sup>218</sup>http://lnotes.State.nd.us/dhs/dhsweb.nsf/e486bc94591422b58625662c007143ec/6521ac9263a78a1b8625666e005 34adf?OpenDocument, accessed March 13, 2003.

North Dakota Department of Human Services, At a Glance (April 2003). http://lnotes.State.nd.us/dhs/dhsweb.nsf/73602c57e0e48b348625666d0070038f/f8fd88c0250ed685862569ed007eb3 85/\$FILE/April%202003%20At-A-Glance.pdf, accessed June 17, 2003.

and subtracts allowed expenses to establish net income. Some of the more common allowable expenses are: taxes and other work related expenses; health insurance premiums; dependent care expenses; child support paid to a non-household member; other deductions may apply.

Individuals in a nursing home are allowed to keep \$50 of their monthly income to meet their personal needs. They also keep enough to cover their health insurance premiums and certain other expenses. If the individual has a family at home with lower income, the individual can give some of his/her money to the family at home.

The Medically Needy component of a Medicaid program requires that members of an eligible Medicaid family unit incur a specific amount of medical expense each month (the recipient liability amount). Medicaid covers the cost of necessary medical care incurred during the rest of that month.

Table 4. North Dakota Medicaid Income Eligibility Levels, 2003

Family Size	Family Coverage LT/E*	Medically Needy LT/E*	SSI LT/E*	Children ages: 6-19 100% FPL	Pregnant Women, child to age 6 133% FPL	Transitional Medicaid 185% FPL
1	\$296	\$500	\$552	\$739	\$982	\$1366
2	399	516	829	996	1324	1841
3	501	666	-	1256	1665	2316
4	604	800	-	1509	2007	2719
5	707	908	-	1766	2348	3266
6	809	1008	-	2022	2689	3741
7	912	1083	-	2279	3031	4215
8	1015	1141	-	2536	3372	4690
9	1117	1200	-	2792	3713	5165
10	1220	1250	-	3049	4055	5640

<sup>\*</sup>Less Than or Equal to

Source: North Dakota Department of Human Services, At a Glance (April 2003).

http://lnotes.State.nd.us/dhs/dhsweb.nsf/73602c57e0e48b348625666d0070038f/f8fd88c0250ed685862569ed007eb3 85/\$FILE/April%202003%20At-A-Glance.pdf, accessed June 17, 2003.

**Table 5. North Dakota Medicare Savings Program** 

Family Size	SLMB	Qualified Individual- 1 135% FPL	Qualified Individual-2 175% FPL	QMB 100% FPL
1	\$887	\$997	\$1293	\$739
2	1195	1344	1742	996
3	1503	1690	2191	1252
4	1811	2037	2640	1509

Source: North Dakota Department of Human Services, At a Glance (April 2003).

http://lnotes.State.nd.us/dhs/dhsweb.nsf/73602c57e0e48b348625666d0070038f/f8fd88c0250ed685862569ed007eb3 85/\$FILE/April%202003%20At-A-Glance.pdf, accessed June 17, 2003.

# North Dakota SCHIP Program<sup>220</sup>

North Dakota's State Children's Health Insurance Program, "Healthy Steps," was implemented in 1998 as a Medicaid expansion. Subsequently in 1999, North Dakota amended its SCHIP plan to include a stand-alone SCHIP program, based on the State Employee Insurance Plan. It provides coverage for preventive services and some dental and vision services for children who do not have health insurance coverage; are 18 years of age or younger; do not qualify for the North Dakota Medicaid Program; or live in families with qualifying incomes.

Healthy Steps is specifically designed to meet the needs of working families who cannot afford health insurance coverage for their children, yet earn too much to qualify for Medicaid. Coverage is available for uninsured children age 18 and younger who live in families with

<sup>&</sup>lt;sup>220</sup> http://www.State.nd.us/childrenshealth/, accessed March 13, 2003.

qualifying incomes. Single 18-year-olds with eligible incomes may also apply. Children who apply for SCHIP but are eligible for Medicaid are referred to Medicaid.

The North Dakota Legislature established the income guidelines on October 1, 1999. To qualify, a family's adjusted gross income (after subtracting childcare costs and payroll taxes such as Social Security tax, Medicare tax, and Federal income tax) must be greater than the Medicaid level, but cannot exceed 140 percent of the Federal Poverty Level.

Table 6. North Dakota SCHIP (Healthy Steps) Income Guidelines

Family Size	Annual Net Income	Monthly Income
1	\$12,404	\$1,034
2	\$16,716	\$1,394
3	\$21,028	\$1,753
4	\$25,340	\$2,112
5	\$29,652	\$2,472
6	\$33,964	\$2,831
7	\$38,276	\$3,190
8	\$42,588	\$3,550
9	\$46,900	\$3,909
10	\$51,212	\$4,268

Source: http://www.State.nd.us/childrenshealth/, accessed March 13, 2003.

Children of farmers and self-employed families are also eligible (not adults), and eligibility is based on the average adjusted gross income for the previous three years.

Children who qualify for SCHIP under the Medicaid expansion program receive Medicaid benefits and no cost sharing is imposed.<sup>221</sup> Those who are enrolled in the stand-alone SCHIP program are subject to program co-payments and deductibles, including:

- \$50 deductible for the first day in an inpatient hospital or a psychiatric or substance abuse inpatient facility.
- \$5 per visit to a hospital emergency room.
- \$2 for each allowable drug prescription.

At the time of program approval, families are informed of cost sharing responsibilities through enrollment information that includes a handbook from the insurance carrier providing coverage and other information. North Dakota SCHIP exempts enrolled AI/AN children from the co-payment requirements, as required by CMS rules.

As of May 2001, 2,441 previously uninsured children age 18 and younger were enrolled in Healthy Steps. <sup>222</sup> Of these children, 51 percent were from urban counties and 49 percent were from rural counties. AI/AN children constituted 9.3 percent of total Healthy Steps enrollment.

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<sup>&</sup>lt;sup>221</sup> http://www.cms.gov/schip/chpfsnd.pdf, accessed March 14, 2003.

http://www.State.nd.us/childrenshealth/enrollment.htm, accessed March 14, 2003.

When State officials launched Healthy Steps in October 1999, they estimated that between 3,800 and 4,000 children met the eligibility criteria established by the legislature. Officials projected that the insurance plan would cover an average of 2,000 children per month during the 1999-2001 biennium. On May 1, 2001, the State covered about 62 percent of the children projected to qualify for Healthy Steps. Efforts to enroll more eligible children continue. Public and private sector collaboration resulted in a Robert Wood Johnson Covering Kids grant, which emphasizes outreach in rural North Dakota and on two AI/AN Reservations. Healthy Steps officials have focused outreach efforts on schools, daycare providers, the medical community, and other entities.

## **DESCRIPTION OF SITE VISIT**

#### Overview

Prior to conducting the site visit to North Dakota, the site visit team contacted Carole Anne Heart, <sup>223</sup> Executive Director of the Aberdeen Area Tribal Chairmen's Health Board, to discuss the Tribes and Reservations within North Dakota, as well as urban Indian health issues and facilities. Ms. Heart provided substantial background information and recommended that we talk further with individuals at the Aberdeen Area Office of the IHS to obtain their views of the specific Reservations and urban area that would be visited in North Dakota. Discussions were then initiated with staff at the Aberdeen Area Office of the IHS to obtain advice, background, and guidance on which communities the site visit team should visit in North Dakota, potential key contacts, and specific issues that should be addressed in the site visit. Further advice and suggestions were obtained from Jim Lyon, the CMS Native American Contact for Region VIII.

For each of these discussions, the project team initially provided the individual(s) interviewed with a copy of the project description and summarized the goals of the site visits. Interviewees were then asked to recommend two Tribes/Reservations<sup>224</sup> and one urban area with an AI/AN facility that provides direct medical services and to provide background information on the sites recommended. The project team also emphasized that, given that only three days were budgeted for visiting two Reservations and an urban area, travel distances were also of some importance. <sup>225</sup>

Based on these discussions, the project team initiated contacts with the Three Affiliated Tribes and with the Spirit Lake Sioux Tribe. Information about the study was emailed and faxed to the Tribal Chairmen's offices and follow-up telephone calls were made on numerous occasions. Unfortunately, , the project team was not able to establish contact with the Spirit Lake Sioux Chairman or his office. At the Three Affiliated Tribes, telephone follow-up did establish contact with the Tribal Health Director who initially indicated the Tribe might participate in the study. However, subsequent conversations were not productive and the project team was informed that the Three Affiliated Tribes were not interested in participating in the study.

<sup>223</sup> Ms. Heart is a consultant to the project and has provided advice and information on a number of issues.

Because none of the Tribes in North Dakota manage their own health facilities under self-governance compacts or contracts, it was not possible to select one Reservation with IHS direct service facilities and one with Tribally managed facilities as was the goal in other sites.

<sup>&</sup>lt;sup>225</sup> Due to scheduling difficulties, the South Dakota site visit required four days to complete.

After it was clear that participation of these Tribes was not possible, the project team selected the Turtle Mountain Reservation in north central North Dakota and the Trenton Indian Service Area in far western North Dakota for site visits. Both of these Tribes agreed to participate in the site visits and scheduling was arranged promptly. The process for recruiting participation in the site visit included: 1) a letter to the Tribal Chairmen at Turtle Mountain and Trenton to inform them of the study and that their Tribe had been selected to participate; 2) follow-up telephone calls to the Tribal Chairmen to confirm their willingness to participate and to identify a coordinator from the Tribe to assist in scheduling and coordination of the site visit; 3) close cooperation between the project team and the Tribal coordinator to determine the individuals who would participate in the scheduled meetings and to obtain background information on unique issues and programs at each site; and 4) development of a formal agenda for each site visit.

Because North Dakota does not have an urban Indian health facility, it was not possible to include this component in the North Dakota site visit.

An all-day meeting in the State capitol building was scheduled, with a number of State agency staff participating. These individuals included the Director of Medical Services; Executive Director, North Dakota Indian Affairs Commission; Director of Economic Assistance Policy; Director of Aging Services; Director of the Healthy Steps program; Director of Medicaid Eligibility (and the Medicare Savings Programs<sup>226</sup>); Healthy Steps Outreach Coordinator; Administrator, Medicaid and Healthy Steps Policy; Director of Rolette County Medicaid program (and member of the Governor's Committee on Aging); Northland Health Care Alliance (a community health center in Fargo, North Dakota); and a representative from Student Health Services, United Tribes Technical College. A complete list of individuals who were interviewed during the site visit is provided in Appendix VII.A of this report

# Description of Turtle Mountain Reservation and Trenton Indian Service Area: Chippewa<sup>227</sup>

The Turtle Mountain Chippewa played a major part in the development of North America and their Reservation is the heart of rich Tribal and spiritual life. Ancestors of the Turtle Mountain Chippewa were primarily trappers, traders, entrepreneurs, guides, and believed they were "caretakers" of the land. As North Dakota's "first family," they occupied an extensive territory extending from the northern and eastern shores of Lakes Superior and Huron. During the three centuries following the European discovery of America, they filtered through the Sault Ste. Marie straits into what are now Michigan, Wisconsin, and Minnesota. They moved into the Dakotas, pushing the Sioux southward in many fierce conflicts over the rich hunting grounds. Eventually, the Red River Valley and North Dakota were prime hunting territory of the

<sup>&</sup>lt;sup>226</sup> The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles." http://www.osec.doc.gov/eda/pdf/33NorthDakota.pdf, accessed March 6, 2003.

Chippewa. The "Red River Cart" trail, which has historical significance, was used in trading between the Chippewas and the Red River Valley communities.

The Turtle Mountain Reservation, home to the Chippewa, is located in the extreme north central portion of North Dakota, approximately seven miles from the Canadian border and near the exact geographic center of the North American continent. The Reservation is almost equally divided between Tribally owned and individually allotted lands. The terrain ranges in elevation from 200 to 2,300 feet above sea level and is dotted with lakes, rolling hills, and a relative abundance of trees. The unincorporated town of Belcourt, North Dakota, is the only community on the Turtle Mountain Reservation. The Reservation was established by Executive Orders of December 21, 1882 and March 29, 1884 on an area of 72,000 acres of land. The 72,000 acres immediately proved to be inadequate for the population of the Reservation. In order to meet the land needs of the people, additional land was allotted in western North Dakota and Montana; this location, the Trenton Indian Service Area, consisting of approximately 69,860 acres, was established by Tribal Ordinance on March 25, 1975 and supported by the Appropriations Act of 1975. The Turtle Mountain Reservation lies within Rolette County, North Dakota; the Trenton Indian Service Area spans six counties across North Dakota and Montana. The Service Area lies approximately 250 miles southwest of the Turtle Mountain Reservation.

#### FINDINGS: NORTH DAKOTA MEDICAID AND SCHIP AGENCY

## Overview

The meetings with State staff were held on the last day of the North Dakota site visit. Theresa Snyder, Tribal Liaison and DHS Program Civil Rights Officer, organized these meetings and developed a comprehensive agenda. Discussions with State staff were conducted in three separate meetings: 1) State Medicaid, SCHIP, Aging Services, Economic Assistance, and Office of Indian Affairs staff; 2) "Reservation Counties" staff, including senior management personnel from counties contiguous to Turtle Mountain and Standing Rock Reservations; and 3) "Non-Reservation Counties—Urban" staff who could provide information on the urban Indian population and how they seek/receive care in the absence of an urban Indian Center. The format of these three meetings kept discussions focused, yet flexible.

An initial draft of this Case Study Report was sent to the State contact and was reviewed by several State staff who participated in the site visit. The State representatives sent a formal letter detailing their comments and this letter is included in Appendix VII.B. These comments have also been incorporated into the body of this Report, where appropriate.

# Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

State agency officials interviewed believed that under-enrollment is an issue in the State, even though there are approximately 52,000 people enrolled in the State's Medicaid program and about 2,300 enrolled in the State's SCHIP program (which represents 6 to 7 percent of the State's population). Data provided to the site visit team, on program enrollment by race and County, indicate that, of the 54,300 people enrolled in Medicaid and SCHIP in October 2002, 22.3 percent were AI/AN.

The Native American Training Institute recently received a Bush Grant that is designed to develop and provide cultural competency training for 500 State DHS agency staff and affiliates/partners. At the time this report was being prepared, training materials were being developed by the Institute. Train-the-trainer programs will follow sometime early next year with an emphasis on 1) children's issues and 2) promoting cultural awareness to create a more culturally competent workforce. This training is seen as important because the interviewees stated that there are cultural issues that are important to providing assistance and services, particularly to AI/AN elders.

#### Barriers to Initial Enrollment

• Medicaid applications require individuals to "cooperate" in establishing paternity related to child support. This application requirement may pose a barrier for those who are reluctant, for a variety of reasons, to identify the absent parent. If Native people believe that the State is attempting to enforce child support collections via the Medicaid application process, they may be deterred from participating in Medicaid. The State, however, noted that the Federal Child Support Enforcement Act (specifically, 42 U.S.C. 1396(a)(45) and 42 U.S.C. 1396 (k) requires States to meet the target Paternity Establishment rates established by the Federal Government – this is not a requirement that the State has discretion over.

# Barriers to Maintaining Enrollment

- Re-determination of eligibility is a responsibility of individual County social service agencies. Each County is free to follow a different process. For example, some offices send a notice and form to individuals through the mail while others make a telephone call and update a form or file. Depending upon the varying methods, this non-standardized application and re-determination process can be burdensome to an applicant.
- AI/AN people enrolled in Medicaid may find it difficult to change Primary Care Providers (PCPs) when they move between one location and another within the State. Interviewees indicated that the need to make a formal change in PCP might contribute to "drop out" of AI/AN people from Medicaid, in some cases.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

State agency interviewees stated they did not think there are very many AI/AN elders in the State: they estimated that the number is probably less than 3,000. Over the past several years, elders have been targeted for outreach, but interviewees did not know if the Reservations were specifically targeted as part of that effort.

Interviewees noted that it is very difficult for people who are disabled to successfully complete the paperwork and the processes necessary to obtain Social Security Disability Income (SSDI) and related Medicare coverage. The Social Security Administration (SSA) provides very limited assistance to the counties and the Tribes on this issue. Interviewees stated that the local

SSA offices provides Medicaid applications to people who apply for SSDI to mitigate the long delay between applying for SSDI and eventually becoming eligible for Medicare coverage.

# Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

State interviewees commented that the Federal/State system for Medicaid and Medicare coverage and financing for AI/AN people is very complicated and inefficient. Several interviewees pointed out the circularity inherent in a Federal system that pays a State system that, in turn, reimburses a Federal agency for services to individuals for whom a Federal Trust Responsibility has been established. Several people argued that, in order for programs to function efficiently and effectively, two steps need to be taken: 1) review and modification of the current inefficient financing/funding system; and 2) clarification of State versus Federal responsibilities in the enactment of meaningful programmatic changes.

Other more specific suggestions made by these interviewees include:

- Increase effective outreach. Coordinated outreach around community events was suggested as a potentially effective strategy for increasing enrollment. For example, the Spirit Lake Casino offers an annual "Health Day" that many seniors attend, at which information on Medicaid/CHIP is distributed. Clinics and school events also are believed to be primary locations where potential applicants seek information, and interviewees said that providing "easy to read" brochures about Medicaid, SCHIP, and Medicare program eligibility and enrollment at these sites could be effective.
- Increase funding for outreach activities. Although most interviewees stressed the importance of outreach, they also noted that there is inadequate funding available to conduct face-to-face outreach or to provide trained outreach workers on each Reservation and at each IHS facility.
- More training for County social services staff. Interviewees suggested that more training on AI/AN cultural and legal issues could be helpful for County social services staff, many of whom have limited understanding of these issues.
- Redetermination processes. In North Dakota, Medicaid eligibility determinations and re-determinations are conducted by County offices and vary considerably across counties. Some counties may be more flexible, less burdensome, and more accessible than others. As a result, there may be considerable variation in the barriers faced by potentially eligible enrollees in Medicaid. The SCHIP program, on the other hand, is managed at the State level, with consistent re-determination processes. Two months before current SCHIP applications expire, forms are sent to individuals for updating. Interviewees indicated that centralizing the Medicaid eligibility and re-determination processes at the State level could result in more consistent eligibility determinations and less "drop out" at the redetermination stage.

- **Recipient liability.** The State imposes recipient liability on Medicaid enrollees who are eligible under the "Medically Needy" category. This issue is a particular problem for AI/ANs who choose to receive Medicaid-covered services through the IHS. The IHS cannot charge them the "recipient liability" amount, but the State then adds this amount to the patient's income, preventing them from qualifying for "medically needy" coverage. Clarification of this issue and development of policies that address the AI/AN population's unique situation is needed. 229
- Clarify the differences among the different State Medicaid program categories. The State of North Dakota currently has 16 categories of coverage groups within the Medicaid program, each of which differs somewhat with respect to eligibility criteria and benefits covered. Thus, Medicaid is a complex program that requires careful explanation and details that are confusing to some people. Some State and County workers indicated that it was difficult to reconcile the varying criteria of each eligibility category, although the policy is to review all eligibility categories to determine whether an individual applicant qualifies for a particular category. Some interviewees recommended that each program have a unique and distinguishable identifying name. This change would help eliminate programmatic confusion and reduce the misperceptions that denial for one Medicaid coverage category means that the individual is not eligible for <u>any</u> Medicaid coverage.
- Develop and distribute Medicare Savings Programs information. Informational materials are not available but the interviewees thought they would be useful as "leavebehinds" at clinics. This would be even more effective if those materials could be discussed with a knowledgeable person at the clinic/hospital.
- **Develop joint CHR/State/County outreach and eligibility assistance programs.** Community Health Representatives (CHRs) work on an ongoing basis with AI/AN people who are likely to be eligible for Medicaid, SCHIP, or Medicare. Interviewees suggested that the State train CHRs in these programs and on eligibility determination. CHRs trained through such a program would then be able to assist AI/AN elders, and others who may be eligible, to better understand the programs and to complete the necessary enrollment processes.

#### FINDINGS: THE TURTLE MOUNTAIN RESERVATION

#### Overview

Ms. Anita Blue, Tribal Health Planner, coordinated planning for the Turtle Mountain Reservation site visit. The site visit included a five-hour group meeting that included the Tribal

<sup>&</sup>lt;sup>228</sup> The medically needy category is optional under the Medicaid Program. North Dakota has chosen to cover this group of individuals, while other States do not offer such coverage, including South Dakota. While recipient liability may pose some problems as it relates to incurring medical expenses it provides an opportunity for individuals and families to become eligible for the Medicaid program that is not available in all States that operate a Medicaid Program.

<sup>&</sup>lt;sup>229</sup> See Appendix VII.B for comments and discussion of this issue provided by representatives of North Dakota State Government.

Planner, Diabetes Coordinator, Director of BIA Social Services, IHS Contracts Specialist, IHS Health Systems Specialist, IHS Administrative Officer/Acting CEO, IHS Medical Records Supervisor, IHS Managed Care Nurse, IHS Benefits Coordinator, IHS Business Manager, Turtle Mountain Tribe Diabetes Coordinator, Tribal Child Welfare Director, TCSCC Coordinator, and the Tribal Child Welfare office manager. The group meeting format proved very effective and resulted in a sharing of information among the meeting participants, as well as with the project site visit team.

## Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Interviewees remarked that working relations with the State are "at arms' length," and "not all that good." Interviewees said that Turtle Mountain has a 65 to 70 percent unemployment rate and they estimated that approximately 30 percent of all Tribal members are eligible for Medicaid coverage.

Generally, interviewees at Turtle Mountain did not express concerns about underenrollment in the SCHIP program. The North Dakota SCHIP eligibility determination and redetermination processes are conducted by the State, unlike the Medicaid program which places responsibility for eligibility determination and redetermination with the County offices. A SCHIP redetermination form is sent out to enrollees two months before the child's enrollment anniversary date. At this point, the form does not contain any previously completed information (i.e., pre-printed). As applications return to the department, the enrollee's name is checked off a master list. In addition, interviewees commended the Covering Kids program and stated that it proved to be very successful in enrollment efforts on Reservations.

#### Barriers to Initial Enrollment:

- The Medicaid application process is reported by interviewees to be "overwhelming." Social workers often merely distribute applications, without taking the time to provide personal assistance. Although some local assistance is available, many still complain that "...this is just too much and I'm not going through all this."
- Transportation to reach the County social service offices to fill out the application is a barrier. The barrier is compounded by the fact that when people do manage to travel to the offices, there sometimes is no one available to assist them.
- Interviewees said that the North Dakota medically needy component of Medicaid is very difficult for AI/AN people. By Federal law, the IHS is the payer of last-resort. If IHS agrees to pay for the \$200-\$300 Medicaid recipient liability for the "medically needy", the State treats this payment as "incurred income" to the recipient. Treating IHS payments for medical expenses as incurred income raises the amount of Medicaid recipient liability to each participant. As a result, the AI/AN individual never gets down to the level where s/he can economically qualify for 100 percent participation. This has a dual effect: It makes the State the payer of last-resort since it will not pay unless its

- policy is met first (contrary to Federal law) and it deters low income AI/ANs from participating in State Medicaid programs.<sup>230</sup>
- Interviewees said that North Dakota has many different eligibility requirements for the different Medicaid coverage categories, thereby creating confusion among potential applicants, current enrollees, and even eligibility workers themselves.
- Interviewees said that the State does not conduct outreach. The perception of the interviewees is that this is because the State does not want to increase its Medicaid population.

# Barrier to Maintaining Enrollment:

• Neither the County nor the State permits access, by Tribal advocates or the IHS, to its Medicaid recipient database. Therefore, it is difficult for these parties to obtain information on people in the eligibility re-determination process.<sup>231</sup>

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Interviewees discussed the following barriers to enrollment in Medicare:

- Interviewees said that some Tribal elders decline participation in Medicare Part B due to their limited income and the relatively high cost of Part B premiums. The Tribe reportedly did consider paying the Part B premium cost for Medicare beneficiaries, but the proposal failed to receive approval from the Tribal Council.
- Interviewees also said it is very difficult for most people with disabilities to undertake the complex paperwork and processes that are necessary to qualify for SSDI and associated Medicare coverage. There is little help available to these individuals and most do not try or, if they are turned down after the first application, they do not continue the process.

# Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

One of the most passionate requests from Turtle Mountain interviewees was for a change in the State's overall enrollment strategy. Because Medicaid eligibility is determined at the County level, the eligibility office is currently located at the County seat approximately eight miles from the Reservation. In this office, there are currently 25 eligibility workers (up from nine a short time ago). Interviewees asked, "When most of the eligible clients in the area come from Turtle Mountain, why should the eligibility office, and all the workers, be located in Rolla?" It was stated that this creates, among other things, a transportation challenge for applicants and enrolled clients alike. At a minimum, interviewees stated, the State/County should consider putting at least one eligibility worker in the IHS facility. The ideal scenario would be to allow the

<sup>230</sup> See Appendix VII.B for State staff's clarifications and comments on this issue.

<sup>231</sup> State staff note that to do so would be a violation of Federal Medicaid law (42 USC 1396a(a)(7)) and would be a felony under North Dakota law (N.D.C.C. 12.1-13-01.) (see Appendix B).

Tribe to make local eligibility determinations, after appropriate Medicaid training and certification.

Other suggestions made by those interviewed at Turtle Mountain include:

- **Permit IHS and Tribal access to State information systems**. The IHS and Tribes do not have access to State software and databases for screening applicants and determining eligibility or obtaining information about expiration dates. It would be useful for the Tribe to have access to a list of Medicaid and SCHIP anniversary dates in order to conduct follow up and help limit attrition.
- **Part B premium.** Interviewees recommended that IHS pay Medicare Part B premiums out of Contract Health Services funds.
- More outreach and education on choosing IHS as PCP. The County office and IHS need to do a better job of informing people that they can continue to use IHS as their PCP under Medicaid.
- Use CHRs to conduct outreach and education. CHRs could be of assistance, particularly in educating elders on the basics of Medicare. For example, they could follow up the letters sent by Medicare just prior to an eligible beneficiary's 65<sup>th</sup> birthday.
- Increase one-on-one outreach and enrollment assistance. Interviewees stressed that one-to-one contact fosters the best public relations for these programs and the greatest difference in enrollment levels. They stated that, currently, the State does not conduct outreach/promotions for any of their social services programs.
- Conduct a marketing campaign to Tribal leaders and other influential Tribal members. Increasing awareness of the importance of Medicaid, SCHIP, and Medicare to health care of AI/AN people would encourage enrollment.
- Improve State, County, and Tribal relations. State, counties, and Tribes need to work together and develop greater trust and collaboration around Medicaid and SCHIP enrollment processes and procedures.
- **Resolve the "recipient liability" issue.** IHS and the State need to agree who is the payer of last-resort so IHS can pay for the recipient liability that discourages participation in Medicaid.

#### FINDINGS: TRENTON INDIAN SERVICE AREA

#### Overview

The Trenton Indian Service Area encompasses over 10,000 square miles in western North Dakota and eastern Montana. This area is not a Federally designated Reservation, but encompasses a large geographic area where AI/AN people were given individual land allotments that are not contiguous. Trenton, North Dakota, is the center of government for the Trenton Indian Service Area and is the locale of the health center that serves AI/AN residents of the

Trenton Indian Service Area. Other AI/AN people who may be temporarily in the area can receive limited services from the health center.

The Trenton Community Clinic is Tribally operated under a P.L. 93-638 contract with the IHS. The Tribe contracts with a medical group practice in Williston, North Dakota, to provide primary care physician and nurse practitioner services at the clinic's facilities. This contract also includes some specialty physician services, with specialists maintaining specific days and hours at the clinic. Mr. Ron Falcon, the Trenton Community Clinic Service Unit Director, coordinated the site visit and arranged a group meeting with clinic insurance and patient registration staff, other clinic staff, and the Tribal Chairperson.

Interviewees at the clinic said that a majority of Tribal members in the area are employed and over one-half have private insurance coverage or are covered by Medicaid or Medicare. Data provided to the site visit team showed that 164 people were enrolled in Medicare Part A and Part B and 10 people reported only having Medicare Part A. Clinic data also indicated that 446 people were enrolled in Medicaid and that 1,203 people had private health insurance.

Of total third-party revenues received by the clinic in 2002, interviewees estimated that about 17 percent were from Medicaid, 10 percent from Medicare, and 73 percent from private health insurance sources. Interviewees at Trenton said that SCHIP may not be an issue as few AI/AN children in the Service Area qualified for the program. However, separate tracking of SCHIP is not done by the clinic data system and, if a child is covered by SCHIP, these revenues are apparently included within the private health insurance category.

In general, interviewees thought that the State agencies are helpful with enrollment issues. They noted that the State sends people to the Tribal health clinic to assist with enrollment and application processes.

## Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Due to a lack of reliable data, interviewees believe there may be under-enrollment of AI/ANs eligible for Medicaid.

#### Barriers to Initial Enrollment

Reasons for under-enrollment and barriers to enrollment that they identified were:

- People do not understand the importance to the Tribe and Tribal members of all eligible people enrolling in Medicaid. Because people can receive free care from the Tribal Clinic, they do not feel it is necessary to enroll in other programs.
- The paperwork associated with applying for Medicaid is complicated and burdensome and prevents many people from enrolling.
- The Tribal population is spread out over 10,000 square miles and transportation to County offices to apply for Medicaid is often not available. The harsh winters in the area make transportation issues of even greater importance during that season.

- Many people are not aware that they may be eligible for Medicaid or that their children may be eligible for Medicaid or SCHIP. The State does little marketing of the programs and there are few benefits counselors to provide information to those who do inquire about eligibility.
- There is also inadequate outreach and enrollment assistance available to provide information about program eligibility and to provide assistance in applying for the programs.
- Interviewees also said that there was a perception among AI/AN people in the area that the County eligibility office staff did not "welcome" AI/AN people and, in some cases, were rude and unhelpful. This discouraged AI/ANs from initiating the processes of applying.

# Barriers to Maintaining Enrollment:

• Interviewees stressed that there is a significant problem with maintaining enrollment for those who succeed in obtaining Medicaid coverage. They stated that re-certification was a problem that resulted in loss of coverage by a significant number of Medicaid enrollees. Tribal health staff are willing to assist individuals in the re-certification process, but the State/County will not/cannot share information with the Tribe on individuals due for recertification

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Interviewees noted that most people who are covered by Medicare, in this area, have also opted to purchase Part B coverage. Health center third-party coverage data provided by clinic staff indicated that nearly 95 percent of Medicare-covered patients had both Part A and Part B. Interviewees had little information on the number who might be enrolled in Medicaid under the Medicare Savings Programs. They said that some people were enrolled in both Medicare and Medicaid, but that they apparently applied on their own behalf.

Interviewees did not identify any strong barriers to enrollment in Medicare or Medicare Savings Programs, but did suggest that many elders had inadequate knowledge and information about these programs.

## Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

Interviewees identified the following strategies as potentially effective in increasing and maintaining enrollment in these programs:

- **Marketing of programs to AI/ANs.** The State should increase marketing and outreach to inform people about Medicaid and SCHIP and eligibility requirements.
- More Patient Benefits Counselors and eligibility workers; one-on-one assistance. It would be helpful if more benefits counselors and eligibility workers were available and could provide more one-on-one assistance with paperwork and other requirements.

- Transportation to County Medicaid offices. Transportation barriers could be addressed by: providing transportation to County offices (through either the Tribe or the County); the County could assign an eligibility worker to assist people with enrollment issues at the Trenton Community Clinic; and/or the State/County eligibility office could make greater efforts to streamline the enrollment processes in order to reduce the need for multiple trips to the eligibility offices.
- "Tickler" list of AI/ANs up for redetermination. The State/County should provide a list of people who are in the re-certification process, to permit Tribal clinic staff to contact and assist these individuals with re-certification.
- Federal government should provide Tribe list of members who are due to become eligible for Medicare. Similarly, the Federal government should provide the Tribe with information on Tribal members who are about to become eligible for Medicare, to permit Tribal clinic staff to contact them and explain Medicare benefits and coverage to them.
- More clinic staff to assist with outreach. It would also be helpful if the clinic had more staff to work with patients to identify those who may be eligible but not enrolled and to provide them with assistance in application processes.

#### **DISCUSSION**

AI/ANs in North Dakota comprise 5.5 percent of the State population and over 22 percent of total Medicaid and SCHIP enrollment, according to State program data. Despite the relatively high rates of enrollment of AI/ANs in Medicaid and SCHIP, interviewees stated that there was under-enrollment in these programs. Generally, both Tribal and State interviewees indicated a relatively good relationship between the State agencies responsible for Medicaid and SCHIP and the Tribes. Both State and Tribal interviewees, however, cited the fact that responsibility for eligibility determination for Medicaid was delegated to counties was a barrier to enrollment in Medicaid. Counties have considerable autonomy to establish application procedures and requirements and redetermination procedures. This creates a system where, in some counties, application procedures may be very complex and require multiple visits to the County offices and, in other counties, application and re-certification procedures may be much less burdensome. Both Tribal and State interviewees suggested that more consistency and State direction of County eligibility and redetermination processes would have a positive impact on enrollment.

Several interviewees mentioned "recipient liability" as a specific barrier to enrollment of AI/ANs in the State's "medically needy" Medicaid program. North Dakota Medicaid sets a specific level of "recipient liability" medical costs based on income that must be incurred prior to Medicaid's "medically needy" program reimbursing for additional incurred medical costs. AI/ANs who receive health care through the IHS cannot be charged for those services. The State, however, considers the waived costs of health care provided to be income to the patient, offsetting the costs of health care that has been provided. Therefore, the costs of health care provided by IHS and not paid for out-of-pocket by the patient, are excluded from determination of medically needy eligibility. This North Dakota policy essentially makes the State the payer of last resort rather than the IHS and prevents AI/ANs with high health care costs from qualifying

for Medicaid coverage. The State reviewers of this Case Study Report were strongly of the opinion that the State is fully compliant with Federal regulations on this issue and note that the Tribal interviewees do not understand the medically needy program rules. Given the differences between the State and Tribal interviewees in their understanding of this issue, it would be helpful if the State would initiate an educational effort to increase understanding of the policy and its basis in Federal regulations.

Other barriers to Medicaid and SCHIP enrollment raised by AI/AN interviewees included: lack of awareness of potential eligibility for and benefits of program enrollment; an expectation that the IHS is responsible for all health care; complex and burdensome application processes; inadequate resources to provide one-on-one assistance to help eligible people enroll; lack of transportation to travel to County offices; and the unwillingness/inability of the State to share information on application and re-certification status of individuals. Similarly, AI/AN interviewees believed that there was inadequate understanding of Medicare and Medicare Savings Programs and greater efforts at outreach and education would be helpful, particularly to elderly AI/ANs living in North Dakota. Interviewed Tribal representatives also cited discrimination and negative attitudes of County eligibility and enrollment workers as a significant barrier to enrollment. State representatives, however, felt that these perceptions were inaccurate and that there was no evidence or complaints reported that supported these allegations.

Interviewed State and County officials acknowledged that there was very little outreach and education on Medicaid and SCHIP conducted by government agencies. State officials also noted that cultural awareness and training of State and County program staff could be useful and encourage greater number of AI/ANs to enroll in Medicaid, SCHIP, and Medicare Savings Programs.

Strategies to overcome barriers to enrollment, raised by interviewees, included: centralizing the Medicaid eligibility determination and re-certification processes as State functions (similar to the SCHIP program); increasing outreach and educational programs on Medicaid, SCHIP, and Medicare to ensure that people understand their potential eligibility and benefits; providing greater resources for one-on-one enrollment assistance; and assigning eligibility workers to Reservations and health clinics. In addition, resolving and clarifying the "recipient liability" issue would be beneficial.

# APPENDIX VII.A: NORTH DAKOTA SITE VISIT CONTACT LIST

# Bismarck

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Shari Doe	Director of Burleigh County Social Srvcs	415 E. Rosser Bismarck, ND 58501- 4058	701-222-6622	08does@State.nd.us
Jackie Vetter	Burleigh County staff	415 E. Rosser Bismarck, ND 58501- 4058	701-222-6622	08retj@State.nd.us

# **Turtle Mountain Reservation**

Name	Title	Address	Phone	Email address
Anita Blue	Tribal Planner	PO Box 900 Belcourt, ND 58316	701-477-0470	Not available
Diana LaFontain	Diabetes Coordinator	Box 6 Belcourt, ND 58316	701-477-6111	Not available
Dinah Brelond	Director BIA Social Services	PO Box 60 Belcourt, ND 58316	701-477-6147	Not available
Ron Desjarlais	IHS Contracts Specialist	PO Box 160 Belcourt, ND 58316	701-477-6111	ronald.desjarlais@mail.ihs.gov
Dale Buckles	IHS Health Systems Specialist	PO Box 160 Belcourt, ND 58316	701-477-6111	dale.buckles@mail.ihs.gov
Todd Bercier	IHS Admin Officer/ Acting CEO	PO Box 160 Belcourt, ND 58316	701-477-6111	todd.bercier@mail.ihs.gov
Carol Hunt	IHS Medical Records Supervisor	PO Box 160 Belcourt, ND 58316	701-477-8425	carol.hunt@mail.ihs.gov
Marilyn Dionne	IHS Managed Care Nurse	PO Box 160 Belcourt, ND 58316	701-477-6111	marilyn.dionne@mail.ihs.gov
Linda Blue	IHS Benefits Coordinator	PO Box 160 Belcourt, ND 58316	701-477-6111	linda.blue@mail.ihs.gov
Jody Morrow	IHS Business Manager	PO Box 160 Belcourt, ND 58316	701-477-6111	jody.morrow@mail.ihs.gov
Shana LaFontain	Turtle Mountain Tribe Diabetes Coordinator	PO Box 900 Belcourt, ND 58316	701-477-0470	shanatrottier@msn.com
Vanessa Davis	Tribal Planning	PO Box 900 Belcourt, ND 58316	701-477-0470	Not available
Bonnie Delorme	Tribal Planning	RR1 Box 121 Belcourt, ND 58316	701-477-0470	bdelorme_2000@yahoo.com
Janice DuBois- Delorme	Child Welfare Director	PO Box 121 Belcourt, ND 58316	701-477-5688	jdelorme@yahoo.com
Barb Poitra	TCSCC Coordinator	PO Box 900 Belcourt, ND 58316	701-427-5255	winona@utma.com
Estelle Morin	Child welfare office mgr	Box 1045 Belcourt, ND 58316	701-477-6111	nativelady2121@yahoo.com

# Trenton Indian Service Area

Name	Title	Address	Phone	Email address
	CHS	P.O. Box 210 Trenton, ND 58853	701-572-8110	Not available
Connie Gerrity	Insurance	P.O. Box 210 Trenton, ND 58853	701-572-8110	Not available
Marsha Buckely	Patient Registration	P.O. Box 210 Trenton, ND 58853	701-572-8110	Not available
Jody Lizotte	CHA/Registration	P.O. Box 210 Trenton, ND 58853	701-572-8110	Not available
Suzanne Moran	CHR/Aging Programs	P.O. Box 210 Trenton, ND 58853	701-572-8110	Not available
Ron Falcon	Service Unit Director	P.O. Box 210 Trenton, ND 58853	701-572-8110	Not available
Karen Johnson	Care Giver	P.O. Box 210 Trenton, ND 58853	701-572-8110	Not available
Cynthia LeCounte	Tribal Chairperson	P.O. Box 210 Trenton, ND 58853	701-572-8110	Not available

# APPENDIX VII.B: COMMENTS ON REPORT FROM NORTH DAKOTA DEPARTMENT OF HUMAN SERVICES

(COPY OF COMMENTS FROM NORTH DAKOTA DEPARTMENT OF HUMAN SERVICES ONLY AVAILABLE IN HARD COPY OF REPORT)

## CHAPTER VIII. OKLAHOMA

#### **BACKGROUND**

#### Overview

This Case Study Report presents background information and findings from a three-day site visit to Oklahoma conducted from December 3 through December 5, 2002. The site visit team consisted of Mary Laschober (Site Coordinator) and Erika Melman of BearingPoint, and Rebecca Baca of Elder Voices, a consultant to the project. The team visited the Cherokee Nation and health facilities in the Tahlequah Indian Health Service (IHS) Service Unit in the northeastern part of the State, Lawton IHS Service Unit Tribes and health facilities in the southwestern corner of Oklahoma, the Tulsa urban Indian health clinic, and State Medicaid/State Children's Health Insurance Program (SCHIP) staff in Oklahoma City. Interviews were held with Tribal and Native American Liaisons for the Oklahoma Health Care Authority, the Project Coordinator for the Oklahoma Covering Kids project, Tribal directors and staff from Cherokee Nation, IHS staff from the W.W. Hastings Indian Hospital, the Lawton Indian Hospital, the Anadarko Indian Health Clinic, the Carnegie Indian Health Clinic, the Lawton Area Health Board, and the Indian Health Care Resource Center of Tulsa. In addition, follow-up telephone interviews were conducted with Tribal health staff from Choctaw Nation, Chickasaw Nation, and Citizen Potawatomi Nation.

An earlier version of this Case Study Report was reviewed by the Centers for Medicare & Medicaid Services (CMS) Project Officer and other CMS staff for accuracy and clarity. Subsequently, the Draft Case Study Report was sent to each of the Oklahoma organizations that participated in the site visit with a request that it be reviewed for accuracy so that comments and additions could be incorporated into the final Case Study Report. Follow-up telephone contacts were made with all of the above mentioned organizations. Comments were received from W.W. Hastings Indian Hospital, the Indian Health Care Resource Center of Tulsa, the Tribal Health Director of the Citizen Potawatomi Nation, and the Business Office Manager at Carl Albert Indian Hospital of Chickasaw Nation.

The comments and recommendations contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or the feasibility of the recommendations. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services, the Indian Health Service, or the State.

# Oklahoma AI/AN Population and Location

The Oklahoma Territory was initially populated by both indigenous American Indian Tribes and by Tribes removed from the southeastern United States by Federal troops between 1820 and 1856. The five southern U.S. Tribes forced into exile to Oklahoma as a result of the Indian Removal Act of 1830 – the Choctaw of Mississippi, the Creek of Alabama, the Cherokee of Georgia, the Chickasaw of Mississippi, and the Seminole of Florida – came to be known as

<sup>232</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/oklahoma/okc-living.asp, accessed April 24, 2003.

the "Five Civilized Tribes" because of their advanced systems of government, education, and law enforcement. Many other Tribes in the northern, eastern, and southern United States were also relocated to Oklahoma Territory. Oklahoma State is currently home to 39 Federally Recognized Tribes, but is one of only three Statewide IHS programs without AI/AN Reservations (with the exception of the Osage Reservation in northeastern Oklahoma). Oklahoma Indians were deeded individual plots of land when Oklahoma became a State in 1907. Today, AI/AN Tribal governments can be found throughout Oklahoma.

According to the 2000 U.S. Census, the AI/AN population living in Oklahoma is more varied than any other State and ranks second only to California in total AI/AN population among U.S. States. In the 2000 U.S. Census, 273,230 Oklahomans identified themselves by race as AI/ANs only and 391,949 individuals identified themselves as AI/AN alone or in combination with another race or ethnicity. AI/ANs comprised about 11.4 percent of the State's population according to 2000 U.S. Census data. The Cherokee Nation, headquartered in Tahlequah, Oklahoma, is the second largest Tribe in the United States with more than 222,000 members. Approximately 90,000 of these citizens live within the jurisdictional boundaries of the Cherokee Nation with the rest residing in California and other U.S. States and countries. 237

The Oklahoman AI/AN population is served by the Oklahoma City Area of IHS, most of which live in rural areas where transportation, employment opportunities, and medical treatment are scarce. A large part of Oklahoma itself is rural, with 39 percent of its population living in non-metropolitan counties in 2001 compared with the national average of 20 percent. Many of Oklahoma's AI/ANs also live in urban areas. Of the 20 cities with the largest urban AI/AN populations among cities with populations of 200,000 or more, Tulsa ranked fifth (18,551 identified as AI/AN alone) and Oklahoma City ranked sixth (17,743 identified as AI/AN alone) according to 2000 U.S. Census data.

AI/ANs living in the Oklahoma City IHS Area compare favorably among all IHS Area AI/AN populations (although they fare less well than the overall U.S. population) with respect to education, unemployment, poverty rates, high birth weight babies to diabetic mothers, and life expectancy at birth (Table 1). The alcoholism rate among Oklahoma AI/ANs is much lower than among most other AI/ANs in the United States, as is the incidence of suicide, depression, and other forms of mental and emotional disorders (data not shown).<sup>241</sup>

<sup>&</sup>lt;sup>233</sup> http://www.salinaok.com/oklahoma.html, accessed April 25, 2003.

 <sup>&</sup>lt;sup>234</sup> Indian Health Care Resource Center of Tulsa, 2002 Annual Report.
 <sup>235</sup> Indian Health Care Resource Center of Tulsa, 2002 Annual Report.

<sup>&</sup>lt;sup>236</sup> http://www.State.ok.us/~oiac/hbpages.pdf, accessed April 25, 2003.

<sup>&</sup>lt;sup>237</sup> The Cherokee people are made up of three Federally Recognized bands. The Cherokee Nation is the largest of the three. Also headquartered in Tahlequah is the United Keetoowah Band of Cherokee Indians, the smallest of the three, with approximately 10,000 Tribal members. The third is the Eastern Band of Cherokee Indians, headquartered in Cherokee, North Carolina, with approximately 12,000 Tribal members (http://www.cherokee.org/Culture/KidsFAQPage.asp?ID=2, accessed May 15, 2003).

http://www.ihs.gov/FacilitiesServices/AreaOffices/Oklahoma/okpre02a.asp, accessed April 25, 2003.

<sup>239</sup> http://www.ers.usda.gov/StateFacts/US.HTM, accessed April 25, 2003.

<sup>&</sup>lt;sup>240</sup> Forquera, R. *Urban Indian Health*. Prepared by The Seattle Indian Health Board for The Henry J. Kaiser Family Foundation. November 2001.

http://www.ihs.gov/FacilitiesServices/AreaOffices/oklahoma/okc-med-demographics.asp, accessed April 24, 2003.

Table 1. Selected Demographic and Health Statistics, Oklahoma City IHS Area, All IHS Areas, and U.S., All Races							
Statistic	Oklahoma City IHS Area	All IHS Areas	United States, All Races				
Percent High School Graduate or Higher, 1990							
	69.2%	65.3%	75.2%				
Percent of Males Unemployed, 1990	12.0%	16.2%	6.4%				
Percent of Females Unemployed, 1999	11.3%	13.4%	6.2%				
Percent of Population Below Poverty Level, 1990							
	27.0%	31.6%	13.1%				
Percent of Total Live Births that are Low Weight (<2,500 grams), CY 1996-1998	6.2%	6.3%	7.5%*				
Percent of Total Live Births that are High Weight (>=4,000 grams), CY 1996-1998	12.2%	12.6%	10.2%*				
Birth Rates with Diabetic Mother, CY 1996-1998	50.8 per 1,000	48.3 per 1,000	26.4 per 1,000				
	lives births	lives births	lives births*				
Leading Causes of Death (as a Percent of Total							
Deaths), CY 1996-1998	28.8%	21.6%	31.4%*				
Diseases of the Heart	18.7%	15.9%	23.3%*				
Malignant Neoplasms	8.5%	14.0%	4.1%*				
Accidents and Adverse Effects	7.0%	6.6%	***				
Diabetes Mellitus	***	4.5%	***				
Chronic Liver Disease & Cirrhosis	4.6%	***	6.9%				
Cerebral Vascular Diseases							
Life Expectancy at Birth, Males, CY 1996-							
1998**	70.4 years	67.4 years	73.6 years*				
Life Expectancy at Birth, Females, CY 1996-							
1998**	76.0 years	74.2 years	79.4 years*				

Source: Demographic and Dental Statistics Section of Regional Differences in Indian Health 2000-2001: Charts Only, Statistics Program, Indian Health Service, Department of Health and Human Services, July 2002.

#### AI/AN Health Services in Oklahoma

The Oklahoma City IHS Area Office provides technical and administrative support for the provision of health care to AI/ANs residing in Oklahoma, Kansas, and a portion of Texas. It has the largest IHS service population in the United States, extending health care to more than 314,000 AI/ANs through its 12 Service Units. Approximately 12,000 inpatient admissions and 1,318,000 outpatient visits are made annually at 7 Indian hospitals and 40 outpatient health centers located throughout Oklahoma, northeastern Kansas, and Eagle Pass, Texas. Additional services are provided through two Urban Indian Programs in Wichita, Kansas and Dallas, Texas, and two demonstration Urban Indian Programs in Oklahoma City and Tulsa. Additional States of the Programs of Pass of Pas

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<sup>\*</sup> CY 1997.

<sup>\*\*</sup> Adjusted for race miscoding.

<sup>\*\*\*</sup>Not a leading cause of death.

<sup>&</sup>lt;sup>242</sup> http://www.ihs.gov/PublicInfo/publications/trends97/tds97pt2.pdf, accessed April 25, 2003.

<sup>243</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/oklahoma/index.asp, accessed April 24, 2003.

Four of the Indian hospitals located in the Oklahoma City IHS Area are operated directly by the IHS and three are operated by Tribes under the Indian Self-Determination and Education Assistance Act of 1975 (P.L. 93-638 as amended). Of the 40 outpatient health centers, 26 are totally managed by Tribes under compact/contract, 12 are operated directly by the IHS, and 2 are operated under contract with AI/AN organizations.<sup>244</sup> Four Tribes with Tribal headquarters in Oklahoma manage and operate their entire health care programs under P.L. 93-638: Choctaw Nation, Creek Nation, Chickasaw Nation, and Citizen Potawatomi Nation.<sup>245</sup>

Because few IHS facilities, whether operated by the agency itself or by Tribes, are located in urban areas, user eligibility rules virtually exclude most urban AI/ANs from services provided through these facilities or purchased from non-Tribal, private sector providers through Contract Health Services. One exception to this general rule is found in Oklahoma. Although originally funded under Title V of the Indian Health Care Improvement Act (PL 94-437, as amended), Tulsa and Oklahoma City urban Indian centers are under a demonstration project as IHS Service Units. These programs operate as IHS direct care Service Units using IHS hospitals for referrals and specialty care (although they are still considered urban programs under the IHS structure). The two demonstration urban Indian health programs are allotted an annual budget out of the pool of IHS funds appropriated for AI/ANs who live on or near Reservations.

#### Overview of Oklahoma State Government

The Oklahoma Indian Affairs Commission's mission, created in May 1967 by the Oklahoma legislature, serves as the liaison between the AI/AN people of the State, Tribal governments, private sector entities, the various Federal and State agencies, and the executive and legislative branches of the Oklahoma State government. The Commission has four goals: 1) create State and Federal legislation; 2) create an advisory committee; 3) develop and implement research projects and reports; and 4) develop cooperative programs between Tribes and State, Federal, local, private entities, health organizations, educational agencies, tourism, and economic development entities. The Commission is made up of 20 members, with 9 appointed members from Oklahoma Tribes and 11 non-voting, ex-officio members representing various agencies within the Oklahoma State government.<sup>249</sup>

# Oklahoma State Medicaid Program<sup>250</sup>

Under its current Section 1115 waiver with CMS, Oklahoma has implemented two distinct managed care delivery systems within its Medicaid program – SoonerCare Plus and SoonerCare Choice. Only a few Medicaid populations are not required to enroll in managed care plans. The Oklahoma Health Care Authority (OHCA) administers SoonerCare and other health-

http://www.ihs.gov/FacilitiesServices/AreaOffices/oklahoma/okc-horizons.asp, accessed April 24, 2003.

<sup>244</sup> Ibid

<sup>&</sup>lt;sup>246</sup> Forquera, 2001.

Authorization for this demonstration project is under IHCIA, Title V, Section 512 (http://www.ihs.gov/NonMedicalPrograms/Urban/Overview.asp, accessed April 25, 2003).

http://www.ihs.gov/ NonMedicalPrograms/Urban/Overview.asp, accessed April 25, 2003; Forquera, 2001.

<sup>&</sup>lt;sup>249</sup> www.oiac.State.ok.us, accessed April 25, 2003.

<sup>250</sup> http://www.ohca.State.ok.us/, accessed April 14, 2003.

related programs. The Oklahoma State Department of Human Services (DHS) determines SoonerCare eligibility, and an enrollment broker under contract to DHS is responsible for enrolling SoonerCare recipients into a health plan (SoonerCare Plus) or with a Primary Care Provider/Case Manager (SoonerCare Choice).

SoonerCare Plus is Oklahoma's Medicaid managed care program for qualified individuals living in Oklahoma City, Tulsa, and Lawton, and the counties that surround these urban areas. OHCA contracts directly with Health Maintenance Organizations (HMOs) on a fully capitated payment basis to provide all medically necessary services covered by SoonerCare Plus. All SoonerCare Plus recipients, including AI/ANs, must choose a health plan and a primary care provider (PCP) from within the plan. However, as of July 1, 2001, AI/AN recipients can still receive services from IHS, Tribal, and urban Indian clinics even if these facilities are not a formal part of an HMO's provider network. Furthermore, AI/ANs do not need a referral from their PCP to receive services from AI/AN providers. DHS pays the facility directly through feefor-service rates. SoonerCare Plus enrollees can change health plans only once a year during the annual open enrollment season (except within 30 days of new plan enrollment).

SoonerCare Choice is Oklahoma's Medicaid program for qualified individuals living in designated rural counties. It is a Primary Care Case Management (PCCM) program through which the State contracts directly with primary care providers throughout Oklahoma to provide basic health care services on a partially capitated payment basis. All recipients must select a Primary Care Provider/Case Manager (PCP/CM). Recipients can change their PCP/CM up to four times at any time during a calendar year. All AI/AN recipients must select a SoonerCare Choice PCP/CM even if they receive all of their health care through an IHS, Tribal or urban Indian clinic. However, as of July 1, 2002, they can continue to receive services through these clinics even if the facility is not signed up with the SoonerCare Choice program and without a referral from their PCP/CM. DHS pays the AI/AN facility directly through fee-for-service rates. Additionally, providers at these facilities may be PCP/CMs through SoonerCare Choice. AI/ANs who need CHS or hospital services that are not available from one of these facilities require a referral from their PCP/CM before the services can be paid.

OHCA is responsible for reimbursement or payment for transportation for clients in both the Medicaid fee-for-service program and the SoonerCare Choice program. This new transportation program, called SoonerRide is available in all 77 counties. SoonerRide is designed to provide free transportation to and from medical appointments (with 24 hour advance notice) for Medicaid enrollees. SoonerCare Plus HMOs are responsible for the transportation of clients enrolled in that program. <sup>252</sup>

select a Tribal or IHS provider as their PCP.

According to OHCA's Native American Liaison, three years ago the IHS and tribes requested more case management control, particularly in rural areas. Therefore, OHCA allowed any IHS or Tribally-based health facility to become a PCP, effective July 1, 2001. However, IHS and Tribal providers are excluded from the automatic selection process for Medicaid or SCHIP recipients who do not actively select a PCP because the State asserts it is too difficult for them to separate AI/ANs from other recipients for this process. Therefore, AI/ANs must proactively

<sup>&</sup>lt;sup>252</sup>http://www.ohca.State.ok.us/Consumer/Medicaid/SoonerCare/SoonerCare%20Plus/plus\_overview.htm; http://www.ohca.State.ok.us/Consumer/Medicaid/Glance/consmed\_glance.htm; accessed April 14, 2003.

All SoonerCare applicants fill out a simple universal two-page application for all family-related Medicaid programs or Oklahoma's SCHIP program. The application can be mailed, brought in person to a local DHS County office, or accessed on-line and submitted electronically; no face-to-face eligibility interview is required. According to the State's website, out-stationed DHS workers also take applications and determine eligibility in many hospitals and clinics across the State. DHS workers also conduct application sessions at local fairs or in schools or community organizations. The application allows self-declaration of income and has no asset test. SoonerCare renewal every six months does not require a face-to-face interview at a County DHS office.

SoonerCare provides health care coverage for infants, children through 19 years of age, and pregnant women who live in households with incomes up to 185 percent of the Federal poverty guideline (FPG) (some of this coverage is provided under Oklahoma's SCHIP program, which is an expansion of the State's Medicaid program). Other groups covered include elderly, blind, and disabled individuals eligible for Supplemental Security Income (SSI) who live in households with incomes up to 100 percent of FPG, medically needy individuals with incomes up to 39 percent of FPG, and medically needy couples with incomes up to 36 percent of FPG. Under the medically needy program, Medicaid coverage is provided to people whose gross incomes modestly exceed the Medicaid income limits but who have high medical bills that reduce their disposable income to below the income limits.

As of May 2002, 44,280 AI/ANs were enrolled the SoonerCare program, with 13,856 in SoonerCare Plus and 30,424 in SoonerCare Choice. OHCA contracted with 170 IHS/Tribal/Urban (ITU) providers through SoonerCare Choice, covering 2,135 AI/ANs, and contracted with 37 I/T/U clinics. <sup>256</sup>

#### **Oklahoma SCHIP Program**

Oklahoma provides health insurance coverage to uninsured children through an expansion of the State's Medicaid program. The State provides SCHIP coverage for children born on or after October 1, 1983, who are six years old or older with family incomes from 101 percent to 185 percent of the FPG and to children under age six in families with incomes between 133 and 185 percent of the FPG. Uninsured children who meet previous eligibility standards must be enrolled in Medicaid.<sup>257</sup>

#### **DESCRIPTION OF SITE VISIT**

#### **Overview**

Prior to conducting the site visit, the team contacted Spero Manson (Division of American Indian and Alaska Native Programs, University of Colorado Health Sciences Center),

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<sup>&</sup>lt;sup>253</sup> http://www.Statecoverage.net/Statereports/multi1.pdf (April 2002), accessed April 2003.

<sup>254</sup> Ibid.

<sup>255</sup> http://www.Statehealthfacts.kff.org, accessed June 10, 2003.

<sup>&</sup>lt;sup>256</sup> http://www.ohca.State.ok.us/Provider/NatAmerSer/Choice AmIndServcs.html, accessed April 14, 2003.

Discussions with CMS on June 10, 2003; http://www.ohca.State.ok.us/Consumer/Medicaid/CHIP/consmed\_chip.htm, accessed April 14, 2003; http://www.aap.org/research/pdf98/ok.pdf, accessed April 25, 2003.

and Pamela Iron (National Indian Women's Health Resource Center, Oklahoma) Technical Expert Panel (TEP) members; Ralph Forquera (Seattle Indian Health Board) and Rebecca Baca (Elder Voices), Project Consultants; Dorsey Sadongei, CMS Native American Liaison, Oklahoma CMS Regional Office; Trevelyn Terry, Tribal Liaison, and Gayla Frittn, Oklahoma's State Medicaid/SCHIP Programs (the Oklahoma Health Care Authority (OHCA)); Hickory Starr, Acting Director of IHS Lawton Service Unit (and ex-CEO of W.W. Hastings Hospital in Tahlequah) and Marjorie Rogers, Oklahoma City IHS Area Office; Denise Exendine, Urban Indian Health Program Branch (and ex-Director of Patient Benefit Coordinators at W.W. Hastings Indian Hospital), and Balerma Burgess, Office of Public Health, Indian Health Service (IHS) Headquarters Office. The team solicited advice on which communities the site visit team should visit, who initial key contacts might be, and which issues specific to the State should be addressed in the study. Interviewees were asked to recommend two Tribes/Reservations and one urban area with a facility that provides direct medical services. The project team also emphasized that, given that only three days were budgeted for visiting two Reservations and an urban area in the State, travel distances were also of some importance.

One criterion that the advisors thought that we should add to our rationale for site selection was that fact that large differences in Tribal communities on the east and west sides of Oklahoma exist. The well-known "Five Civilized Tribes" inhabiting primarily the east side of the State are larger Tribes, relocated there by the Federal government in the mid-1800s from southern U.S. States. In contrast, small Tribes that migrated from the Northern Plains area centuries ago or were forcibly relocated to Oklahoma, mainly from western and northern U.S. States, inhabit the west side of the State. Another difference exists between many of the western Oklahoma Tribes and the eastern Five Civilized Tribes: Historically, descendancy rather than blood quantum defines Tribal membership in the Five Civilized Tribes; in contrast, in many of the western Oklahoma Tribes (in the Anadarko Area, for example), Tribal membership is qualified by ¼ blood quantum. We were told that these differences have lead to a large diversity of cultures. As well, sometimes the smaller Tribes feel forgotten, with the western Oklahoma Tribes viewing the larger membership of the eastern Tribes as giving those Tribes greater leverage with IHS funding for hospitals, clinics, and Contract Health Services, and as having greater voting influence with the State. Additionally, advisors said that the smaller Tribes in western Oklahoma do not bill third parties as aggressively as do the eastern Tribes. Advisors recommended we visit one Tribe in each of the eastern and western sides of the State.

Based on these discussions, the project team selected Cherokee Nation/Tahlequah Service Unit and Lawton Service Unit for the Tribally based site visits, and the Tulsa Urban Indian Health Center for the urban area site visit. Additionally, the team was scheduled for inperson meetings with OHCA staff in Oklahoma City. At that time we were also to meet with several Tribal health representatives from Oklahoma Tribes that contract/compact with the IHS to manage their own health facilities: Choctaw Nation (located in the Talihina Service Unit in the southeastern corner of Oklahoma), Citizen Potawatomi Nation (located in the Shawnee Service Unit in central Oklahoma), Creek Nation (located in the western portions of the Claremore and Tahlequah Service Units in northeastern Oklahoma), and Chickasaw Nation (located in the Ada Service Unit in south central Oklahoma). Due to inclement weather, however, the Tribal health representatives were not able to travel to Oklahoma City and were interviewed by telephone following the site visit.

Cherokee Nation is primarily a compacting Tribe on the east side of the State. Cherokee has an on-site Medicaid/SCHIP eligibility worker from DHS out-stationed at its main IHS-operated hospital. Cherokee Nation has been assertive with third-party billing and, through compacting with IHS, has reached out to a variety of vendors. Cherokee Nation has a mix of Tribally directed health clinics and an IHS-directed hospital (W.W. Hastings Hospital) in addition to "a lot of Contract Health Services." Even though IHS runs Hastings Hospital and its associated outpatient clinic, we were told that IHS consults frequently and regularly with Cherokee Nation and has conducted joint outreach training of CHRs and other Tribal staff. Additionally, Hastings Hospital received CMS "seed money" grants for two years to hire two patient benefits coordinators. This generated increased third-party revenues, which in turn were used to hire three additional benefits coordinators. We were also told that although many other IHS and Tribal facilities employ patient benefits coordinators, they are not as active and assertive with outreach outside of their facilities. Advisors suggested that the Hastings Hospital would be useful to visit for "best practices" ideas.

The Lawton Service Unit serves the small Tribes that migrated from the Northern Plains area centuries ago or were forcibly relocated to Oklahoma from western and northern U.S. States inhabit the west side of the State. The Lawton Service Unit encompasses a relatively urbanized area, is bordered by Texas, and serves seven Tribes. We were told that Lawton would be a good contrast to Cherokee Nation as the "seven small Tribes will probably never compact/contract with IHS to manage their own health facilities because of their small sizes."

Advisors unanimously recommended we visit the Indian Health Care Resource Center of Tulsa, which has more active program outreach, third-party billing, and program development than the other Urban Indian clinic in the State, the Oklahoma City Indian Clinic.

The site visit team relied heavily on local Tribal and Urban Indian Health Center key contacts to determine which groups and individuals the team should speak with and at which places and times, in accordance with the Case Study Design Report. The team sent a list of people the site visit team would like to interview to an identified key contact at each site. The list included Tribal leaders, Tribal health directors and Tribal health board members, IHS service unit directors, Contract Health Services directors, community health representatives/community health aides, Title VI directors/elder organization leaders, IHS hospital and clinic staff including alternative resource specialists, case managers, billing specialists, and patient benefits coordinators and counselors, urban Indian center and clinic staff, and other organizations that serve the AI/AN community (e.g., Area Agencies on Aging, out-stationed or County Medicaid/SCHIP eligibility workers, Indian alcohol treatment centers, Indian education programs, and Tribal or County social services agencies). The individuals and organizations with whom the site visit team met in Oklahoma or conducted follow-up telephone interviews are listed in Appendix VIII.A.

## Description of Cherokee Nation and the Tahlequah Service Unit<sup>258</sup>

The Cherokee Nation Tribe originated in the area of the United States that would become North and South Carolina. Their relocation by the Federal government in accordance with the Indian Removal Act of 1830 is recorded in history as the "Trail of Tears." One of the Five Civilized Tribes, the Cherokees are widely known for their written language and advanced forms of government and education long before the influx of white settlers into Oklahoma territory.

Cherokee Nation operates four health centers in northeastern Oklahoma at Sallisaw, Stilwell, Salina, and Jay under the auspices of P.L. 93-638, the Indian Self-Determination Act, as well as several other Tribally managed outpatient clinics, satellite nursing clinics, and a mobile health unit. The Cherokee Health Authority also provides services in environmental health, mental health, social work, community health, and home care, some of these within the physical plant of the W.W. Hastings Indian Hospital at Tahlequah. The entire health program is directed from the Cherokee Tribal complex, also in Tahlequah.

The Tahlequah Service Unit provides health care to 30,000 members of the Cherokee and Creek Indian Tribes, as well as to AI/ANs from many other Tribes living in the State, covering a 4,300- square-mile area. The five counties served are about 80-percent rural, but include two towns – Muskogee with a population of around 40,000 and Tahlequah with about 9,700 people. The medical center of the Tahlequah Service Unit is the JCAHO-accredited, 60-bed at W.W. Hastings Hospital in Tahlequah, operated by IHS. The facility offers a full range of inpatient and outpatient services. Tertiary referrals are made to major hospitals in nearby Muskogee, Tulsa, Fort Smith, Arkansas, or Oklahoma City. Hastings Hospital logs approximately 4,000 adult and pediatric admissions per year (accounting for some 14,000 inpatient days), with 1,000 newborn admissions. Over 130,000 outpatient visits are handled annually. The facility maintains professional affiliations with the Schools of Nursing and Optometry at Northeastern State University, with the College of Pharmacy at Southwestern State University, and with students, interns, and residents from Oklahoma's three medical schools.

# **Description of Lawton Service Unit<sup>259</sup>**

The city of Lawton, 85 miles southwest of Oklahoma City, has a population of nearly 82,000 and is the third largest city in Oklahoma. The Lawton Service Unit encompasses 10 counties in the southwestern corner of Oklahoma, where 25,000 members of the Caddo, Comanche, Delaware, Fort Sill Apache, Kiowa, Kiowa-Apache, and Wichita Tribes are concentrated. The Lawton Service Unit includes the Lawton Indian Hospital, the Anadarko Health Center, the Carnegie Health Center, and a health station at the Riverside Indian School, all operated by IHS.

Situated in Lawton, the Lawton Indian hospital has 45 beds and a staff of 16 physicians who attend over 400 deliveries a year, perform nearly as many surgical procedures, serve 2,100 adult and pediatric patients annually and attend 65,000 outpatient visits. The full-service facility

<sup>&</sup>lt;sup>258</sup>http://www.ihs.gov/FacilitiesServices/AreaOffices/oklahoma/okc-tahlequah-su.asp, http://www.ihs.gov/FacilitiesServices/AreaOffices/oklahoma/okc-Tribal-cherokee-nhcp.asp, and http://www.cherokee.org/Services/Health.asp, accessed 3/31/03.

<sup>259</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/oklahoma/okc-lawton-su.asp, accessed 3/31/03.

offers a full range of inpatient and outpatient care. The hospital continually provides medical rotations for intern students in pediatrics and obstetrics/gynecology from the Hillcrest Community Hospital in Oklahoma City.

A new health center has recently been opened at Anadarko, a small rural community of 6,500 about 64 miles from downtown Oklahoma City and 41 miles from Lawton. With a staff of three physicians and one physician assistant, the Anadarko Health Center handles nearly 35,000 outpatients visits each year, about 13,000 of them physician-attended. The facility performs all the usual outpatient and community services, and includes a clinical laboratory, radiology department, and dental clinic. Also in Anadarko is the Riverside Indian School, site of an IHS health station. This facility and nearby Carnegie Health Center are staffed through outreach services rather than by resident full-time physicians.

#### **Description of IHS Compacting/Contracting Tribes**

Choctaw Nation. The Choctaw Nation of Oklahoma, located in the southeastern part of the State, traces its ancestry to Mississippi and Alabama. The Choctaws were the first of the five southern "civilized" Tribes of the United States to be moved to Oklahoma. The southeastern corner of Oklahoma makes up the IHS Talihina Service Unit, its boundaries following roughly the lines of the Choctaw Nation drawn by the U.S. Government in 1855. Since February 1, 1985, the Choctaw Nation under the auspices of P.L. 93-638, the Indian Self-Determination Act, has managed all health care facilities within the Talihina Service Unit. The Choctaw Nation Health Service Authority operates one hospital at Talihina (Choctaw Nation Health Care Center that provides inpatient and outpatient care), four comprehensive health centers (Broken Bow Clinic at Broken Bow, Hugo Clinic at Hugo, McAlester Clinic at McAlester, and Rubin White Clinic at Poteau), the Choctaw Nation Diabetes Treatment Center at Talihina, and a telemedicine network over a State communications system to three remote sites of Broken Bow, McAlester, and Hugo. Choctaw Nation health facilities provide comprehensive health care to some 47,849 AI/ANs. Aliahom Choctaw Nation health facilities provide comprehensive health care to some 47,849 AI/ANs.

As early as 1917, the Choctaws and Chickasaws pooled their finances to build the first Talihina Indian Hospital – a two-story wooden building with 60 beds, dedicated initially to patients with tuberculosis. The Choctaw Nation of Oklahoma is also the first Tribe to build their own hospital with their own funding. <sup>262</sup>

*Citizen Potawatomi Nation*. Citizen Potawatomi Nation is located near Shawnee, Oklahoma, in the central portion of the State. Mainly originally from Indiana and Kansas, the Tribe is the largest of the eight Federally Recognized Potawatomi Tribes and the ninth largest Tribe in the United States, with a Tribal membership of over 26,000. Citizen Potawatomi Nation owns and operates several business enterprises, but no casinos. <sup>263</sup>

The Citizen Potawatomi Nation Health Complex, funded from IHS compact funds and Tribal enterprises and operated by Citizen Potawatomi Nation, provides medical services to

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<sup>&</sup>lt;sup>260</sup> http://www.choctawnation.com, accessed May 1, 2003.

<sup>&</sup>lt;sup>261</sup> http://www.ihs.gov/facilitiesservices/areaoffices/oklahoma/okc%2Dtalihina%2Dsu.asp, accessed May 2, 2003.

<sup>&</sup>lt;sup>263</sup> http://www.potawatomi.org/services/ent.htm, accessed May 2, 2003.

Tribal members and other AI/ANs in its service area. The Health Complex currently experiences about 50,000 outpatient visits a year. In addition to providing Contract Health Services and other various outpatient services, the Health Complex provides free and reduced cost outpatient prescription drugs to Tribal members and their families. Because Oklahoma has no State-sponsored pharmacy assistance program, the Health Complex's pharmacy program covers the majority of prescription drug needs for Tribal members according to the Citizen Potawatomi Nation interviewee. The program is funded through IHS compact funds and Tribal enterprises. Health Complex staff refer AI/ANs to Carl Albert Indian Health Facility in the Ada Service Unit (Tribally-operated by the Chickasaw Nation) for tertiary care if the hospital has good facilities and a good reputation in the required medical specialty. Others are referred to private hospitals in the area, depending on the type of care needed and a hospital's reputation for providing care in that specialty. Private hospital services are paid out of Contract Health Services funds.

The Citizen Potawatomi Nation operates a unique program called the Health Aid Foundation. The Foundation provides financial assistance of up to \$750 per year to Tribal members mainly to cover durable medical equipment not covered by third-party insurance and unavailable through the Tribal health system. Upon successful application to the Tribe, the money can be used to reimburse a Tribal member's out-of-pocket expenses for contacts, dentures, hearing aids, glasses, etc. 266

*Chickasaw Nation.* One of the Five Civilized Tribes, the Chickasaws were relocated to Oklahoma from the central Appalachian Mountain region of Kentucky and Tennessee and formed their nation in 1855 from the western half of the Choctaw Nation. The boundaries of their nation today coincide almost exactly with those of their nation before Statehood.<sup>267</sup>

The Chickasaw Nation operates three health centers under the Indian Self-Determination Act within the boundaries of the Ada Service Unit in south central Oklahoma: Tishomingo, Ardmore, and Durant Health Centers. The administrative area of the Chickasaw Nation has its Tribal headquarters at Ada, a town of 17,500.<sup>268</sup> The Chickasaw Nation is largely credited for the IHS/Tribal cooperative effort that resulted in construction of the 53-bed Carl Albert Indian Hospital at Ada, operated by Chickasaw Nation. A general medical and surgical hospital, the facility is Medicare-approved and offers general and specialty services in medicine, surgery, obstetrics, and pediatrics. Also available are audiology, anesthesiology, respiratory therapy, radiology, physical therapy, and surgical pathology services. The hospital admits approximately 2,400 patients annually and manages another 68,000 outpatient visits each year.<sup>269</sup>

http://www.potawatomi.org, accessed May 2, 2003; and comments from Mr. Bill Thorne, Director of Health Services, Citizen Potawatomi Nation and Director of Citizen Potawatomi Nation Health Center.

<sup>&</sup>lt;sup>265</sup> Interview with Bill Thorne, Director of Health Services, Citizen Potawatomi Nation and Director of Citizen Potawatomi Nation Health Complex.

<sup>&</sup>lt;sup>266</sup> Ibid.

http://www.ihs.gov/FacilitiesServices/AreaOffices/oklahoma/okc-Tribal-chickasaw-nhcp.asp, accessed March 31, 2003.

<sup>&</sup>lt;sup>268</sup> Ibid.

<sup>&</sup>lt;sup>269</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/oklahoma/okc-ada-su.asp, accessed March 31, 2003.

# **Description of the Tulsa Urban Area**<sup>270</sup>

Tulsa is located at the convergence of the geographic boundaries of the Osage, Cherokee, and Muscogee (Creek) Nations. Although Oklahoma's Tribal governments are located in rural areas, the metropolitan area of Tulsa is home to a large interTribal population comprised of members of many AI/AN Tribes. Cherokee and Creek Tribal members are most numerous. According to the 2000 U.S. Census, Tulsa is the fifth largest city in terms of an urban Indian population among cities with a population of 200,000 or more, with 18,551 AI/ANs reporting only this racial category on the 2000 Census and 30,227 reporting this race alone or in combination with other races or ethnicities. These numbers do not include many more AI/ANs who live in the Tulsa metro area.

The Indian Health Care Resource Center of Tulsa (IHCRC) has been operating as an urban Indian health clinic for 26 years. Three years ago, IHCRC moved into a new facility and in 2002 gained accreditation from the Accreditation Association for Ambulatory Health Care. IHCRC staff is currently developing plans to expand services by constructing a medical wellness center. IHCRC interviewees estimated that the Center serves AI/ANs from well over 100 Federally Recognized Tribes, including about 35 Oklahoma Tribes.

As described previously, IHCRC operates under a demonstration project as an IHS direct care Service Unit, using IHS hospitals for referrals and specialty care (although they are still considered urban programs under the IHS structure). Under the demonstration project, the Tulsa urban Indian health programs is allotted an annual budget out of the pool of IHS funds appropriated for AI/ANs who live on or near Reservations and have access to CHS funds. However, as a private, nonprofit Oklahoma corporation, it also operates through grants (IHCRC has a grants writer on staff), contracts, philanthropic support, patient fees and third-party insurance reimbursements from SoonerCare, Medicaid, Medicare, and private insurance. IHCRC employs two "eligibility workers" who conduct third-party insurance screening and provide insurance program application assistance. IHCRC staff estimated that 60 percent of the Center's funding comes from IHS, 13 percent from grants, and 27 percent from third-party revenues and patient self-payment. According to the 2002 Annual Report of IHCRC, the Center received the following distribution of funds from third-party or self-pay sources:

<sup>270</sup> Information obtained from the 2002 Annual Report of the Indian Health Care Resource Center of Tulsa, unless

Forquera, R. *Urban Indian Health*. Prepared by The Seattle Indian Health Board for The Henry J. Kaiser Family Foundation, November 2001..

Table 2. Insurance Payers for Children and Adults, Indian Health Care Resource Center of Oklahoma								
January 1, 2002 to October 31, 2002								
	Medicaid/		Private	Sliding Fee,	Full			
Population	SCHIP	Medicare	Insurance	Self-Pay	Self-Pay			
Children (birth to age 19)	44%	0%	1%	54%	1%			
Adults	Ω0/-	20/-	10/_	Q50/ <sub>-</sub>	20/			

Source: 2002 Annual Report of the Indian Health Care Resource Center of Tulsa

IHCRC employs more than 70 full- and part-time staff, contracts for health care specialists, and operates a formal Volunteer Program. It provides a full range of acute care, preventive care, diagnostic, chronic disease management, Indian family, and other services. Prenatal care is provided through a contract with the University of Oklahoma College of Obstetrics and Gynecology. As appropriate, patient referrals are made to the IHS Claremore Indian Hospital, to IHS Contract Health and to other providers for specialty medical care. Additionally, IHCRC contracts with the University of Oklahoma's Psychiatry Department to assist with behavioral health clinical oversight and protocols. Traditional medicine is available if requested, but requires a referral. IHCRC runs a large number of other health care and prevention programs including "Healthy Start" (a nurse-community linked State program for pregnant women and children under age two) and WIC. Since 1995, IHCRC has also been a participant in Tulsa's Community HealthNet – a consortium of Tulsa's not-for-profit "safety net" community health providers that deliver affordable health care to Tulsa's medically needy populations. IHCRC coordinates with other Community Health Centers to better understand how the urban AI/AN population relates to the Center's service population.

#### **Description of Other Organizations Interviewed**

In 1997, The Robert Wood Johnson Foundation established *Covering Kids: A National Health Access Initiative for Low-Income, Uninsured Children* to help States and local communities increase the number of eligible children enrolled in health insurance coverage programs. Oklahoma conducted three pilot projects under the Covering Kids grant, one of which targeted AI/AN communities in the State. The goal of the project, led by the South Central Consortium beginning in 1999, was to build a community outreach network across a five-County region in southern Oklahoma with a large AI/AN population. The project then focused on identifying, assisting and enrolling eligible children into health insurance programs. Strategies included hiring an outreach coordinator to work with community and civic organizations, schools, businesses, health plans and providers; out-stationing enrollment workers in neighborhood settings; and recruiting student volunteers to conduct door-to-door enrollment activities in targeted areas.<sup>272</sup>

Prior to conducting our site visits in Oklahoma, we contacted the project coordinator of the lead grantee in Oklahoma – Nele Rogers of the Oklahoma Institute for Child Advocacy – to discuss her perceptions about barriers to AI/AN Medicaid/SCHIP program enrollment and

<sup>&</sup>lt;sup>272</sup> http://www.coveringkids.org/projects/pilot.php3?PilotID=113, accessed June 2002.

suggestions for increasing enrollment among the pilot project's target populations. Findings from this discussion are included in the section of this report entitled "Findings: Statewide Organizations."

# FINDINGS: OKLAHOMA MEDICAID OFFICE AND OTHER STATEWIDE ORGANIZATIONS

#### **Oklahoma Health Care Authority**

#### Overview

At the OHCA offices in Oklahoma City, the site visit team interviewed OHCA's Tribal Liaison and OHCA's Native American Liaison for SoonerCare's Managed Care Programs. The OHCA Tribal Liaison believes that most AI/ANs are aware of SoonerCare's availability, and although there is some AI/AN under-enrollment in the program, she does not think it is widespread. Primary causes discussed mirror several of those described by the Oklahoma Tribes interviewed: fear of the State sharing application information with State child support enforcement staff; some AI/ANs seeking insurance assistance only when an acute need arises; not actively selecting a PCP upon enrollment in SoonerCare; custody issues relating to AI/AN children living with extended families; and a lengthy redetermination application and process. The OHCA interviewees believe there is some, but not serious, under-enrollment in the Medicare Savings Programs<sup>273</sup>, although they were not sure of the causes.

The OHCA Tribal Liaison expressed concern that AI/AN enrollment in SoonerCare may become a more serious problem in the future due to State budget cuts over the past two years that have reduced the State's outreach and enrollment activities in several ways. First, fewer DHS outreach and eligibility workers are available for out-station placement at IHS or Tribal health facilities. Previous to the budget cuts, an IHS or Tribal facility could request an out-stationed DHS worker for whom the State would pay one-half of his/her salary as long as the facility paid the other half. For example, Choctaw Nation has a SoonerCare office immediately adjacent to its hospital. However, it is currently "nearly impossible" for an AI/AN facility to receive funding from the State for a new out-stationed worker position, and some facilities that have a funded position are in danger of losing it. Because of the shortage of DHS eligibility workers Statewide, counties have the option to "pull back" eligibility workers from IHS or Tribal facilities if needed. For instance, the OHCA Tribal Liaison said that W.W. Hastings Hospital in Tahlequah might lose its out-stationed DHS eligibility worker if the local County government decides he is needed at the County's DHS office. The OHCA Native American liaison did not know the number of out-stationed DHS workers in Oklahoma's Indian country at the time of the interview. (Interviewees at W.W. Hastings Hospital estimated it at 23 or 24, mostly located in IHS hospitals and clinics.)

<sup>&</sup>lt;sup>273</sup> The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

Prior to State budget cuts, the State had developed SoonerCare outreach materials (mostly written) incorporating features intended to raise AI/AN program awareness including, for example, photographs of AI/ANs and separate listings of AI/AN PCPs. The outreach materials were used in general and targeted AI/AN State outreach activities. The State also attended AI/AN health fairs, providing materials and application assistance on site if requested. Additionally, the State provided a continuous-play videotape to any health facility in the State requesting it (not only Tribal or IHS facilities) that included general information about SoonerCare and the application process and a self-referral option section for AI/ANs. (The OHCA Tribal Liaison said the State does not believe the tape has been very effective.) The State also ran Public Service Announcements on Tribal radio stations and placed ads in local and Tribal newspapers. The OHCA Tribal Liaison said the State had been very willing to respond to individual community preferences regarding the best methods and modes for education and outreach. Currently, Oklahoma prohibits any SoonerCare outreach activities. OHCA now only attends some health fairs at which it promotes AI/AN materials only. It also provides SoonerCare applications to a limited number of targeted schools located in very poor areas with high numbers of AI/AN children. The State currently has no outreach activity that specifically targets AI/AN elderly.

On the positive side, the OHCA Tribal Liaison believes that Tribally operated facilities in Oklahoma are much more assertively and pro-actively billing third parties. Additionally, the State recently changed SoonerCare application requirements to allow mail-in or electronically-submitted applications. The State is also working on cooperative agreements with Medicaid agencies in border States (Texas and Arkansas) to receive payment for health care provided in Oklahoma's schools and Tribal and IHS facilities to out-of-State Medicaid/SCHIP recipients.

The State interviewees suggested that additional strategies for maintaining or increasing current AI/AN enrollment levels include targeted AI/AN consumer education about program benefits individually and to Tribes, carried out at the local community/Tribal level; funding to increase staff at Tribal and IHS facilities that can provide screening and one-to-one application assistance; and increased or restored funding to allow DHS outreach and eligibility worker outplacement at Tribal and IHS facilities.

Finally, the OHCA Tribal Liaison stated that the OHCA has a good working relationship with Tribes and local IHS staff. However, she noted that frequent Tribal staff turnover makes maintaining good and open relationships difficult and time consuming. The OHCA liaison tries to maintain good relationships by attending all Oklahoma Area Inter-Tribal Health Board meetings and by participating in several Tribal listservs. She also regularly invites local IHS and Tribal staff to comment on proposed SoonerCare changes and attend OHCA meetings, although she said there is generally poor IHS and Tribal attendance at these meetings. According to the OHCA liaison, "[T]he door's open, but there's only so much we can do."

The OHCA interviewees noted that as a consequence of State budget shortfalls, Oklahoma's financial eligibility requirements for children ages 1 through 18 and certain aged, blind, and disabled individuals were scheduled to be reduced and the optional Medically Needy program was scheduled for elimination, in early 2003. Scheduled Medicaid service reductions included fewer covered inpatient hospital days and elimination of the adult dental program. She

said this change would affect AI/ANs because, even though the Federal government provides a 100 percent funding match for AI/AN Medicaid recipients, the State would also have to cut benefits equally for AI/ANs due to the "law of comparable benefits" among all Medicaid recipients. OHCA estimated that approximately 93,000 Oklahomans out of 625,000 people served annually could be impacted by either a loss of eligibility (79,700) or a reduction in benefits (13,000).<sup>274</sup> In December 2002, the State announced the elimination of the Medically Needy program and the described cuts in services, but preserved eligibility levels for others.<sup>275</sup>

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

The OHCA interviewees believe there is some under-enrollment in SoonerCare primarily due to the following factors:

- The accessibility of SoonerCare applicant or recipient records by State child support enforcement staff. Any State worker has access to DHS information, discouraging some AI/ANs from completing an application for fear that the State will use the information to pursue child support from an absent parent.
- Reluctance to enroll in SoonerCare until incidence of an acute medical need when the perceived benefits of the program outweigh the application time and effort.
- Non-selection of a PCP upon SoonerCare enrollment by some AI/ANs because of their option to self-refer to an IHS or Tribal clinic. Some AI/ANs are auto-assigned to a non-AI/AN PCP which becomes an issue when referral care is needed because the individual must receive prior PCP approval. At that time, lack of awareness, lack of transportation, resistance to going to a non-AI/AN facility, and other barriers can complicate the referral process. Shared stories of such complications also reduce incentives for some AI/ANs to enroll in SoonerCare. However, the OHCA interviewees noted that SoonerCare recipients can change PCPs without cause up to three times a year. Therefore, this is not a serious barrier to AI/ANs who live in SoonerCare Choice counties because all IHS/Tribal providers can become their PCP. This is a more serious problem in SoonerCare Plus counties because the latter is not true, although AI/AN SoonerCare recipients can still switch to an HMO PCP for referral care.
- Inability of grandparents who do not have legal custody of grandchildren a common occurrence in Indian Country according to the OHCA Tribal Liaison to apply for SoonerCare on behalf of their grandchildren. However, the OHCA interviewee thinks that the State can "deem" custody even if it has not been legally established. (This issue was not confirmed.)

<sup>&</sup>lt;sup>274</sup> http://www.ohca.State.ok.us/General/Media/NewPress/19SEPT02prelease.htm, accessed May 5, 2003.

http://www.ohca.State.ok.us/general/media/newpress/12dec02prelease.htm, accessed May 5, 2003.

The OHCA Tribal Liaison also remarked that even when AI/ANs are enrolled in SoonerCare, some do not bring their SoonerCare card to IHS or Tribal clinics because they know they can receive services without it. This creates billing problems for AI/AN clinics.

#### Barriers to Maintaining Enrollment

• The primary barrier to maintaining enrollment, according to the OHCA Tribal Liaison, is that the State's redetermination application is currently 21 pages long and the application must be completed every six months. Because of the lengthy redetermination process, some AI/ANs do not maintain enrollment once an acute care incident that motivated their initial application is over. Both of these issues have been brought to the State's attention and OHCA is working with DHS on simplifying the form. However, the Oklahoma legislature will not allow SoonerCare to implement a 12-month redetermination process.

#### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

The OHCA interviewees believe there is some AI/AN under-enrollment in Medicare Part B but did not know the seriousness of the problem or possible causes (because OHCA does not administer or oversee the Medicare program). They estimated there is also some, but not serious, under-enrollment in the Medicare Savings Programs. The OHCA interviewees were not sure of the causes although they believe that some AI/ANs do not enroll due to inadequate understanding of the programs' benefits.

#### Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

OHCA interviewees discussed several strategies OHCA currently employs to enhance AI/AN program enrollment:

- **Tribal consultation process.** OHCA actively participates in the Tribal consultation process with Tribal governments, IHS, and the Oklahoma Area Inter-Tribal Health Board to improve the health status of AI/ANs in the State. Additionally, OHCA is collaborating with IHS and Tribes on the Community Health Representatives (CHR) project and the Asthma Collaborative project. Additionally, SoonerCare applicants previously had to go in-person to a County DHS office to apply, but this is no longer the case. OHCA interviewees said there are many places (including the OHCA website) to obtain an application which can be mailed or electronically submitted. They reported this has reduced a major barrier to enrollment for all eligible people, including AI/ANs.
- Regular training for State staff. The OHCA interviewees said that SoonerCare has a regular training schedule for staff located at all types of health care clinics and facilities across the State. They emphasized that SoonerCare conducts regular training for IHS facility staff. OHCA has only a small budget for AI/AN CHR training. However, the OHCA Tribal Liaison said the CHR program was "grossly cut by the BIA and, furthermore, OHCA has not found the CHR training to be very effective."

<sup>&</sup>lt;sup>276</sup> For a description of these projects, please visit the State's website referenced in footnote 25.

- Covering Kids project. As another method for increasing SoonerCare enrollment for all Oklahoman populations, OHCA participated in the early 2000s in the Covering Kids project in Oklahoma, partnering with the Oklahoma Institute for Child Advocacy, the Oklahoma Primary Care Association, the Oklahoma State Department of Health, and Oklahoma DHS.
- Legal assistance resources for AI/ANs. The OHCA interviewees believe that legal assistance resources are available in Indian Country in Oklahoma to assist AI/ANs with program denials or other legal issues. Oklahoma has Legal Aid offices in every County which work with OHCA to understand and resolve program issues for both AI/ANs and non-AI/ANs. The OHCA Tribal Liaison said she has never heard that there is a lack of legal aid. She also thinks that transportation is not usually a barrier to program use. SoonerCare HMOs are required to provide transportation for enrolled members and SoonerCare recipients in PCCM have access to a transportation broker through SoonerRide, with no limit on distance. Additionally, she believes that many AI/ANs have access to CHRs who can provide transportation although some Tribes require SoonerCare members to use SoonerCare resources.

In response to suggestions for additional strategies to increase SoonerCare and Medicare Savings Programs enrollment in Oklahoma, OHCA's interviewees said they did not think that the CHR outreach program is, or would be, effective. Their opinion is that CHRs are overwhelmed already with work and would not likely be able to take on the additional training needed to help others understand the complicated public/private/IHS/Tribal insurance and health care systems. The OHCA interviewees, however, did suggest that the following strategies might improve enrollment in SoonerCare, Medicare Part B, and the Medicare Savings Programs:

- **Systematic consumer education.** OHCA stated there have been no systematic efforts by any organization to educate all consumers, and AI/ANs in particular, about the benefits of the SoonerCare program or about the benefits of third-party revenues for IHS and Tribal facilities. The interviewees believe such education emanating from either the State, Tribes, IHS, and/or CMS would improve enrollment.
- **Dispel stigma of SoonerCare.** Consumer education could also be targeted towards ridding the SoonerCare and Medicare Savings Programs of their welfare stigma.
- One-on-one application and redetermination assistance. Although some IHS and Tribal facilities have billing clerks who assist AI/ANs with application and redetermination paperwork, they suggested that more of this type of one-to-one assistance is needed to increase AI/AN enrollment in all public health insurance programs.
- Outstationed eligibility workers. Increased funding for DHS outreach and eligibility workers who could be out-stationed at IHS and Tribal health facilities would improve enrollment. However, the Native American liaison for SoonerCare's managed care program did note that some Tribes are not "real enthusiastic about having a Tribal employee do eligibility determination, preferring that the State bring the bad denial news" to Tribal members.

• Outreach activities at the Tribal and/or community level. OHCA interviewees recommended that all outreach activities be conducted at the Tribal/community level.

#### Other Issues

According to OHCA interviewees, IHS is often slow in implementing changes to its billing and encounter computer software systems, not keeping current with changes in State Medicaid programs and billing systems. For example, Oklahoma's new Medicaid claims system is not compatible with RPMS and some Tribal systems. In particular, interviewees said that "IHS always wants to do something different [than States] with its RPMS system," and "The IHS needs a better appreciation of the fact that each State's Medicaid and SCHIP programs are different." They believe that Tribal programs are much better about pro-actively adapting their systems to Medicaid program changes.

#### **Oklahoma Covering Kids Project**

#### Overview

The project coordinator for the lead grantee for the Covering Kids grant in Oklahoma (Nele Rogers of the Oklahoma Institute for Child Advocacy) said their pilot project found that Tribal perceptions of SCHIP and Medicaid span a wide spectrum of opinion. She said that some Oklahoma Tribes see the Medicaid program as a "gift" because it does not require a State match, which reduces fluctuations in funding levels: "The program is like a mortgage payment to the Tribes as it helps to fulfill the Federal Trust Responsibility." Conversely, she said that other Tribes have a negative view of the SCHIP and Medicaid programs due to perceived burdensome application requirements, welfare stigma, and expectations that IHS funding should be increased to provide more comprehensive services for AI/ANs. Nonetheless, she said that many of the Federally Recognized Tribes in Oklahoma appear to be increasingly active in promoting SCHIP and Medicaid, having watched the success of the Cherokee Nation in markedly improving program enrollment and third-party billing.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Based on the pilot project's outreach activities, Nele Rogers reported that a primary barrier to AI/AN enrollment in SoonerCare is a shortage of providers. She said that OHCA States publicly that there are sufficient numbers of SoonerCare providers in the State. However, she noted that while this may be true for family practice physicians, the pilot project staff did not find it to be true for specialists during the period 1999 to 2001. The provider shortage reduces AI/AN incentives to enroll in SoonerCare if they believe they will not be able to find a SoonerCare provider willing to provide health care services (or were previously enrolled in the program and could not find a provider).

#### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

The interviewee did not cite any barriers to enrollment in Medicare or the Medicare Savings Programs.

#### Strategies to Increase Enrollment in Medicaid and SCHIP

Nele Rogers discussed two activities the pilot project team believes constitute "best practices" for increasing AI/AN enrollment in SoonerCare:

- Patient Benefit Advocates. She said the Cherokee Nation became excited about SCHIP after it hired its first Patient Benefit Advocates (PBAs) in 1999. These individuals were stationed at Cherokee Nation health care clinics and hospital and charged with matching qualified families with available public resources (e.g., WIC, Food Stamps, and SoonerCare). According to Ms. Rogers, the impact of PBAs was almost immediate, with SoonerCare revenue increasing almost \$3.8 million over the first year of their hiring. She believes that the key to the success of the PBAs all of whom were AI/ANs was that they were hired from within the Cherokee Nation health care system, representing "faces the patients already knew" (such as clinic insurance clerks). In the first year of the project, PBAs distributed 18,000 letters to potential eligible families describing SoonerCare and the PBAs' role in outreach and application assistance.
- AmeriCorp Volunteers. Nele Rogers said that over 4,000 applications were completed and submitted by AmeriCorp volunteers through outreach and application assistance during the pilot project. This averaged over 900 completed applications per volunteer by the end of funding for the Covering Kids pilot project. (The project did not document the number of these applications that resulted in successful enrollment or how many were rejected due to incomplete applications.) The program started with 20 volunteers, but ended up with 12 working at six sites. Nele Rogers said that the pilot project, however, had difficulty in finding the "right" people for this type of work. Once found, however, they can be effective for increasing enrollment by providing one-on-one application assistance to AI/ANs who need it.

#### FINDINGS: CHEROKEE NATION/TAHLEQUAH SERVICE UNIT

#### Overview

Cherokee Nation operates six outpatient centers and two satellite nursing clinics under contract with the IHS.<sup>277</sup> Each of their outpatient centers employs a Patient Benefits Advocate (PBA). Our meeting with Cherokee Nation Tribal health staff included representatives from their Health Services Division, Human Services Division, and Contract Health Services. These divisions were represented by the Executive Director of Health Services, the Senior Director of Information and Referral, the Manager of Information and Referral, the Special Projects Officer for Health, and the Patient Benefits Advocate and Contract Health Services Coordinator. Prior to the site visit, Cherokee Nation representatives asked us to distribute a "voluntary participation form" to participants in all of our meetings in the area, which we did. A copy of the form, as approved by CMS and Cherokee Nation, is attached to this report as Appendix VIII.B.

In a separate meeting with staff from the IHS-operated W.W. Hastings Hospital, we met with the Business Office Manager, three Patient Benefits Coordinators (PBCs), and the DHS

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<sup>&</sup>lt;sup>277</sup> http://www.cherokee.org/Services/HealthClinics.asp, accessed April 15, 2003.

eligibility worker out-stationed at the hospital. (The Acting CEO of Hastings Hospital was out ill the day of our interview.) The DHS eligibility worker has been employed at the hospital for the past two years, with 50 percent salary funded by DHS and 50 percent by the IHS. Hospital staff said they requested an out-stationed worker on site because their previous DHS outreach worker was not in-house. The DHS worker's primary job is to process SoonerCare applications for children and pregnant women who are patients at the hospital.

Cherokee Nation health staff interviewees believe that there is serious AI/AN under-enrollment in SoonerCare, Medicare Part B, and the Medicare Savings Programs among the area's AI/AN eligible population. Hastings Hospital staff interviewees echoed this, noting they believe it is substantially low for non-IHS or Tribal health facility users. Cherokee Nation interviewees identified the most serious "gap" between eligibility and enrollment as "at-risk" children living with extended families who have no legal custody of the children. Under-enrollment was stated to be due to both barriers to initial enrollment and to "drop out" at re-enrollment verification. Barriers identified and discussed by meeting participants included lack of outreach outside of health care facilities and consumer education about program benefits, failure to adequately screen and assist health care facility users due to high patient-to-staff workloads and staff turnover, access to "free" health care at IHS and Tribal facilities, low SoonerCare and Medicare provider reimbursement rates, fear of losing current assets after program application, DHS County office issues, and lengthy SoonerCare redetermination and Medicare Savings Programs forms.

Both Cherokee Nation and Hastings Hospital staff interviewees said that hiring of PBAs/PBCs in the clinics and hospital have been key to increasing AI/AN enrollment in Medicare and SoonerCare since 1997, as has the DHS out-stationed workers. Hastings Hospital staff emphasized that the "aggressive" work by the five PBCs employed by the hospital (currently they have four PBCs on staff) are in large part responsible for the high SoonerCare and Medicare Part B program enrollment percentages among AI/ANs living in the area. Interviewees further noted that it is extremely important to get all key players in the "public benefits arena" together, trained, and collaborating so they can see how all public benefits programs and application processes are inter-related, as well as understand the variety of needs of AI/ANs. Hastings Hospital interviewees called attention to the very positive working relationship in the area among SSA, IHS, Cherokee Nation, and State Medicaid/SCHIP office staff. (Cherokee Nation interviewees remarked that "the State is hard to deal with, but not as hard as they used to be.") Hospital staff said the former CEO devoted a lot of time to strengthening these relationships, for example, by inviting DHS staff to attend Veteran Affairs training at the hospital and vice versa. Hastings Hospital interviewees also noted the importance of Cherokee Nation's recent increased involvement in providing social services through the Tribe.

Additional suggestions interviewees provided for increasing program enrollment included community education about program benefits, health facility staff program training, increased funds to hire additional PBAs/PBCs and the re-establishment of State PBA/PBC certification programs, transportation assistance, increased SoonerCare and Medicare provider payment rates, and greater confidentiality guarantees for SoonerCare application information.

<sup>&</sup>lt;sup>278</sup> A separate report being submitted under this project's contract discusses estimates of under-enrollment of AI/ANs in Medicaid, SCHIP, and Medicare for the State of Oklahoma.

Hastings Hospital staff noted that it frequently takes a long time to obtain approval for Social Security Income (SSI) or Social Security Disability Income (SSDI) benefits. This in turn slows Medicare and Medicaid eligibility rates for disabled AI/ANs in the community.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

According to Cherokee Nation health staff interviewed, anything that inhibits third-party billing and revenue collection reduces incentives for Tribal or IHS health care facilities to actively engage in efforts to increase enrollment in third-party insurance programs. The health staff interviewees said, for example, that the 100 percent Medicaid pass-through reimbursement is slow for the Cherokee Nation because Oklahoma's Medicaid program does not pay them until the Federal government pays the State.

Cherokee Nation health staff interviewees believe that, despite the success of the PBA program, there is serious AI/AN under-enrollment in SoonerCare. Hastings Hospital staff agreed that this is a large problem, particularly for non-hospital and clinic users, although it has no actual figures to measure this or to measure the effects of under-enrollment on resulting mortality rates or increased health risks. Hospital staff members conduct no outreach outside of the hospital, such as with Head Start or social services programs, because they are too busy. Staff believes there is also some under-enrollment among hospital users due to their limited time to help all patients who need assistance.

#### Barriers to Initial Enrollment

Initial enrollment barriers discussed with Cherokee Nation Health staff reflect the experiences of those directly interviewed as well as a summary of enrollment barriers gathered through the PBA Coordinator's discussions with PBAs over the past three years. Interviewees described the following SoonerCare enrollment barriers for AI/ANs in their area:

According to Cherokee Nation staff, the most serious "gap" between eligibility and enrollment pertains to "at-risk" children living with an extended family that has no legal custody of the children. First, a child's eligibility is based on the extended family's household income, often making these children ineligible for SoonerCare. Second, no mechanism exists to take account of "informal foster care" for determining eligibility when the extended family is not the child's legal guardian. For example, grandparents may not want Temporary Assistance for Needy Families but do want medical coverage for their "informal foster" grandchildren but cannot apply on the child's behalf because they are not the child's legal guardian. Third, extended families are often concerned that any public program application will alert the State to their situation, causing the State to place the child in the formal foster care system. Fourth, there is a fear that the State will use information on the public program application to pursue child support from the absent parent or to establish that one of the parents is an illegal immigrant. Interviewees referred to this as "punitive eligibility policy" for Medicaid-eligible children because the State's Medicaid system allows the sharing of application information with State child support enforcement and other State personnel. Interviewees said the State "is not supposed to do this, but it does." They stated this is a "huge issue in Cherokee Nation."

- Cherokee Nation outpatient clinics train PBAs to screen and assist clinic patients with program application. However, their system frequently breaks down because a clinic's "front-line" staff WIC staff, registration staff, admission clerks fail to screen and refer potentially eligible patients to the PBAs. They said this is due to a high patient load and substantial staff turnover (interviewees were not asked to provide data on either patient load or staff turnover). Additionally, they said it is very difficult for a single PBA at each clinic to keep up-to-date with Oklahoma's and Arkansas's Medicaid/SCHIP program changes; training time takes them away from the clinic. Hastings Hospital staff, particularly the PBCs, also said they assist with SoonerCare applications and redetermination forms, but said this places a substantial workload on the staff who "need to know as much as DHS eligibility workers to help clients and follow-up for them."
- Cherokee Nation interviewees noted that there is an impression by the "AI/AN public" as a whole that the IHS and Tribal health care facilities are free, being paid for by the government, and that the government will continue to fund them. Therefore, the "AI/AN public" sees no reason to enroll in other health insurance programs.
- According to Cherokee Nation interviewees, the lack of providers who will accept SoonerCare in some Oklahoma counties because of "very low Medicaid reimbursement rates" deters some AI/ANs from applying to SoonerCare. The low Medicaid reimbursement rates also provide little incentive for Cherokee Nation clinics to dedicate any resources toward increasing program enrollment.
- According to Cherokee Nation health staff, many AI/ANs do not want to provide confidential information to government agencies due to mistrust of government agencies and services, or even to health care facilities, as they feel these people "are looking into their lives." Hastings Hospital staff, however, said that they have only experienced minimal resistance from a few patients to enrolling in SoonerCare, who they find generally want the coverage. However, Hastings Hospital interviewees did confirm that some AI/ANs have reported they are not treated well at the DHS County office, and that it is faster to process their application at the hospital than at a DHS office due to less waiting time and more one-on-one application assistance.
- Both sets of interviewees said that rapid changes in government programs are difficult for consumers/patients to keep up with and understand, exacerbated by high illiteracy rates among area AI/ANs.
- Hastings Hospital interviewees noted that some AI/ANs do not want to apply for Medicaid because they are afraid they will lose their land, house, or other public benefits.

#### Barriers to Maintaining Enrollment

• According to Cherokee Nation interviewees, "every County office does redetermination differently," causing confusion among SoonerCare recipients as well as people trying to

assist recipients with redetermination.<sup>279</sup> Interviewees believe that some changes at the State level do not filter down to the County level and County workers are not always adequately trained on changes to the State's computer system.

- At the beginning of the interview, Hastings Hospital staff immediately brought up the issue of redetermination for SoonerCare, indicating it is a serious problem, particularly for their obstetrics and pediatrics patients. The staff said these patients have "real problems" with the redetermination form because it screens for all public welfare programs, thus requiring information on assets and other questions that are not required for the initial SoonerCare application. The entire form needs to be completed, however, even if the person is only re-certifying for SoonerCare. The interviewees said that OHCA has told them that patients only need to complete the sections of the form required for SoonerCare redetermination, but staff said this solution is often too confusing. Recipients may not be sure which sections to complete and worry they will be denied SoonerCare if they do not complete the entire form.
- Additionally, Hastings Hospital staff said that recipients have only one month (or sometimes less if the mail is late) to return the form. If they miss the deadline, interviewees reported that often the entire family is dropped from the program. According to the interviewed staff, "OHCA lost about 20,000 clients in two months when they started the review." Interviewees also said that many of their patients report they never receive the form; and some do not realize they can just mail in the form, believing they have to return it in-person at the County office. Many patients return their redetermination form to Hastings Hospital staff because they feel more comfortable there than at the County office.

#### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Hastings Hospital staff believe there is some AI/AN under-enrollment in Medicare Part A, particularly females, although they view it is a relatively small problem (rating it as a "3" on a scale of 1 to 10, with 10 being a substantial problem). Some women do not realize they are eligible for Medicare as the spouse of a Medicare recipient. Additionally, AI/ANs who retire before age 65 often do not realize they must actively apply for Medicare through the local Social Security office upon reaching age 65. Another issue for some disabled and elderly AI/ANs is that they believe they will lose their Veterans Affairs health benefits if they enroll in Medicare or even request information about the program.

Cherokee Nation and Hastings Hospital health staff interviewees believe there is substantial AI/AN under-enrollment in both Medicare Part B and the Medicare Savings Programs. Medicare Part B under-enrollment barriers include:

• Medicare beneficiaries with Part A do not understand why they need Part B benefits. In addition, they do not realize they will have to pay higher Part B premiums if they enroll after their open enrollment period upon turning age 65. Hastings Hospital staff said

<sup>&</sup>lt;sup>279</sup> It was beyond the scope of work for this project to establish whether or not every County office actually processes redeterminations differently.

educating patients about Part B benefits consumes between one-half to two-thirds of their PBCs' time.

• According to Cherokee Nation interviewees, the lack of providers who will accept Medicare assignment in some Oklahoma counties reduces clinics' incentives to ensure that Medicare eligible AI/ANs are enrolled in Part B.

Medicare Savings Programs barriers for AI/AN Medicare beneficiaries described by those interviewed include the following:

- Cherokee Nation interviewees said that the Medicare Savings Programs application in Oklahoma is very long, currently at 21 pages. Additionally, the staff believes that program enrollment requires a face-to-face interview at DHS offices. Some eligible AI/ANs do not want to go to a DHS office due to welfare stigma and transportation is also a "big issue." Hastings Hospital staff interviewees added that some elderly are resistant to going to a County DHS or Social Security Office because they do not feel they are treated as respectfully as they should be. However, they are "not resistant to coming to the eligibility worker at Hastings" because he is located in a culturally appropriate setting. He also "takes the slower, right approach" for AI/AN people. Interviewees emphasized that a culturally sensitive approach is very important for encouraging AI/AN elderly to enroll in Medicaid programs.
- According to Cherokee Nation health staff interviewees, some local DHS offices do not tell clients about the Medicare Savings Programs even when DHS staff is aware of them. Cherokee Nation clinics train PBAs on what to tell patients to ask for at the DHS office for the Medicare Savings Programs to help alleviate this barrier.
- Staff also said that the DHS County offices provide "a lot of misinformation, especially about long-term Medicaid benefits," perhaps due to inadequate County staff detailed training on these benefits. For example, AI/AN elderly are often fearful of losing their homes if they sign up for Medicaid. According to those interviewed, DHS County office staff often do not provide application assistance or information that would help allay these fears.

#### Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

Cherokee Nation and Hastings Hospital currently employ a variety of strategies to improve enrollment in the public insurance programs:

- Cherokee Nation clinics require patients needing CHS services to first show evidence of application to third-party insurance programs. Although Hastings Hospital does not require this, it does require that all patients present a card indicating prior insurance screening at the hospital's registration desk before services can be received.
- Access to DHS program on-line screens. Cherokee Nation clinics have access to DHS program on-line screens and sometimes are able to use the out-stationed DHS worker from Hastings Hospital to help process applications.

- Cherokee Nation clinics have considered training PBAs to flag medical charts of patients nearing age 65 to remind them to apply for Medicare Part B and the Medicare Savings Programs, but PBAs have been too busy to implement this strategy. A few years ago, PBAs did a one-time mailing to near-65-year-olds to provide application information, which they felt was somewhat effective but expensive (interviewees were not asked to supply verification data regarding effectiveness or cost).
- Cherokee Nation clinics have tried to train CHRs to screen their clients for program eligibility but it has not been very effective due to CHR time constraints and complicated Federal/State/County/IHS/Tribal insurance programs and health care systems.
- DHS eligibility worker out-stationed the hospital. Hastings Hospital interviewees said the DHS eligibility worker out-stationed the hospital and his direct access to the DHS system is an "excellent resource and very important" to SoonerCare and Medicare Savings Programs enrollment of the hospital's patients.
- A Veterans Affairs representative visits Hastings Hospital once a week to provide patient education, which staff said is very helpful.
- Good working relationship among IHS, Cherokee Nation, the State's OHCA, other State Medicaid Offices (e.g., Arkansas), and SSA offices. Hastings Hospital staff interviewees also said that an important strategy for increasing their third-party revenues was the establishment of a good working relationship among IHS, Cherokee Nation, the State's OHCA, other State Medicaid Offices (e.g., Arkansas), and SSA offices, facilitated by the hospital's former director, Hickory Starr. He also encouraged staff from these agencies to come to the hospital to conduct staff training and patient education to reduce the time PBAs need to be away from the hospital.
- Patient Benefits Coordinators. Both Cherokee Nation and Hasting Hospital staff interviewees said that hiring of PBAs/PBCs since 1997 in the clinics and hospital have been key to increasing AI/AN enrollment in Medicare and SoonerCare (although they were not asked to provide figures to document the additional increase in enrollment by the number of PBAs or PBCs hired). An estimated 50 percent of Hasting Hospital's budget is currently derived from third-party resources. In 1997, CMS's Center for Medicaid and State Operations offered "seed" money to fund a staff position for a full-time PBC at the Hastings Hospital. Between FY 1997 and FY 2000, W.W. Hastings Hospital increased its Medicaid collections by \$3.5 million through implementation of a PBC program.280 According to Mr. Starr, the increased revenues allowed the hospital to improve care and services for all patients, as well as to hire additional PBCs. These activities in turn increased SoonerCare, Medicare, and other insurance program enrollment and revenues. At the time of our interview, the hospital had four full-time PBCs on staff, two of which focused on adults, another on pregnant women, and a third for children. The hospital is planning to hire a fifth PBC soon.

<sup>&</sup>lt;sup>280</sup> http://www.cherokee.org/NewsArchives/November2000Page.asp?ID=9, accessed April 27, 2003.

Hasting Hospital staff described several other important factors in addition to the PBC program that have contributed to the substantial increase in third-party revenues. These include doctor and nurse education about the importance of third-party resources to the facility's financial well-being; adoption of a common program terminology among providers, the business office, and the financial office; frequent staff meetings and training; trained certified coders; community awareness of the responsibility to enroll in the public programs; a "customer service/business operations" approach by the facility; having a DHS eligibility worker on site; requiring each of the hospital's departments to be responsible for their own budget; conducting systems analyses; and establishing a well-functioning billing infrastructure.

Cherokee Nation health staff interviewees were not aware of any State outreach programs since the Robert Wood Johnson Foundation-sponsored Covering Kids project in Oklahoma described above. Hastings Hospital staff said DHS used to fund outreach positions until about a year ago which they found to be very effective for increasing SoonerCare enrollment. Interviewees provided the following suggestions for increasing AI/AN program enrollment:

- Community education. Cherokee Nation and Hasting Hospital interviewees said that community education is needed regarding IHS fund limitations and how the Medicaid, SCHIP, Medicare, and the Medicare Savings Programs can benefit Tribal members individually as well as the community. Continuing education is needed for the "AI/AN public" (e.g., consumers, physicians, nurses) as to why additional funding is needed and the types of public health programs that are available. They believe that community education and outreach is best done at the Tribal level, for example, through Tribal community meetings that often attract elderly Tribal members, at senior centers, and through simple brochures for consumers.
- Program training for front-line health facility staff. Both sets of interviewees stressed the need for program training for front-line health facility staff, such as admissions and billings clerks, as well as additional training for PBAs/PBCs on all public benefit programs. Hastings Hospital staff previously attended State-sponsored training but DHS budget cuts have drastically reduced such opportunities ("DHS has not held a training for a long time"). PBAs/PBCs currently rely on newspapers, the Internet, and informal networking to keep them informed of changes in the Federal and State programs. They also learn through their on-site DHS eligibility worker and a Veterans Administration representative who comes to the hospital once a week. They stressed, however, that they have "no systematic way to keep up." Interviewees requested implementation of frequent and regular program training on all State and Federal public benefits programs.
- Hastings Hospital staff suggested development of a "training sheet" on how to complete SoonerCare, Medicare Savings Programs, and Medicare applications and redetermination forms. They also suggested establishment of a mailing list, e.g., through the Internet or a newsletter, directed to all key stakeholders to facilitate regular communication and networking. They noted that someone "in-house" with access to the State's computer system would probably be the best person to maintain such a mailing list.

- SoonerCare application information be made inaccessible to State child support enforcement agency. Cherokee Nation interviewees advocated that SoonerCare application information be made inaccessible to State child support enforcement workers and other State staff. (Interviewees wondered whether this might be done under the new HIPAA rules to protect medical information.)
- Increase Medicare and State SoonerCare reimbursement rates. Cherokee Nation interviewees recommended that Medicare and State SoonerCare reimbursement rates be increased to attract more providers to serve program recipients and to improve Tribal and IHS facility incentives to increase program enrollment. This would also help prevent cost-shifting to Tribal funds to pay for non-Tribal-covered services that are used when a Tribal member cannot find a Medicare/Medicaid provider.
- **More Patient Benefits Coordinators**. Both Cherokee Nation health staff and Hastings Hospital staff expressed the need for more PBAs/PBCs to handle patient workloads.
- More transportation resources. Cherokee Nation interviewees said that more transportation resources are needed to access SoonerCare services, which would provide greater incentives for area AI/ANs to enroll in the program. The SoonerCare program provides transportation to access medical services with contractors (SoonerRide) but not to Cherokee Nation. Cherokee Nation provides a lot of transportation through their CHRs, but it cannot be reimbursed by the State for these services.
- Certification program for Patient Benefits Coordinators. Interviewees noted that the State used to certify PBAs/PBCs as outreach workers for SoonerCare. These certified applications were processed much quicker than non-certified ones. Both Cherokee Nation and Hastings Hospital interviewees suggested that Oklahoma should again provide a certification program for PBAs/PBCs to become outreach workers for public benefits programs.

#### FINDINGS: LAWTON SERVICE UNIT

#### Overview

Our site visit to the Lawton Service Unit of the IHS included a three-hour group meeting with approximately 25 patient benefit coordinators (PBCs), registration clerks, billing clerks and supervisors, Contract Health Services personnel, and business office staff from the IHS-operated Lawton Indian Hospital, Anadarko Indian Health Clinic, and Carnegie Indian Health Clinic. The group included several CHRs from Comanche Nation. We were told that CHR responses to interview questions were based on their experiences from a Comanche Nation-sponsored Medicare/SoonerCare Enrollment Outreach Pilot Project in which CHRs and Tribal Emergency Medical Services personnel conducted outreach and application assistance for these programs throughout 2002.

A large portion of the group meeting consisted of questions from the interviewees directed to the site visit team about particular programmatic aspects of the Medicare, Medicare

Savings, and SoonerCare programs. The amount of questions from interviewees indicated a clear need for additional program training and information resources in this area.

Prior to the group meeting, the site visit team met briefly with the Southwestern Oklahoma Inter-Tribal Health Board to obtain their endorsement for the site visit interviews in the Lawton Service Unit. Health Board members expressed their concern that Oklahoma's planned reduction in SoonerCare eligibility for low-income people from 185 percent to 115 percent of FPG would negatively affect IHS funds. They believe that because this reduction would likely cause fewer AI/ANs to be eligible for SoonerCare, IHS would collect less SoonerCare revenues and more AI/ANs would have no alternative to IHS or Tribal facility services.

There was consensus among the Lawton Service Unit group interviewees that there is significant SoonerCare under-enrollment of Tribal members, which has increased over the past two years due to State budget shortfalls. Group interviewees also unanimously agreed that enrollment in Medicare Part A for eligible elderly AI/ANs was *not* perceived to be a problem in their area because people about to turn 65 receive information "early" from CMS.<sup>281</sup> However, they said that under-enrollment in Medicare Part B *is* a substantial problem for Tribal members in their area.<sup>282</sup> Awareness of the Medicare Savings Programs, even among IHS hospital and clinic staff, was very low. Barriers described during the interviews included lack of County DHS staff training, cultural sensitivity, and communication; low availability of SoonerCare providers; SoonerCare redetermination problems; unaffordable Medicare Part B premiums and beneficiary lack of understanding of Part B benefits; fear of losing assets upon program enrollment; and lack of awareness of alternative program enrollment options (i.e., mail or on-line), with inadequate reliable transportation thus cited as a enrollment barrier.

Group interviewees suggested several strategies for increasing SoonerCare, Medicare Part B, and Medicare Savings Programs enrollment. These included IHS development of an inhouse outreach system; CMS, IHS, and State cooperation to develop and implement educational programs, and provide more education materials, targeted to both AI/AN consumers and health care staff and geared particularly to IHS/Tribal systems, to help elderly and qualifying disabled persons understand 1) the types of services Medicare Parts A and B cover, 2) why they should pay the Part B premium, 3) the relationship between Medicare and private health insurance, and 4) the benefits and applications process for the Medicare Savings Programs; more publicity emphasizing that AI/ANs enrolled in SoonerCare can choose an IHS or Tribal provider as their primary care physician; and language simplification in the SoonerCare redetermination letter to individuals.

Several group interviewees believe that many elder AI/ANs in Oklahoma are not eligible for Medicare because they were employed by Federal programs prior to 1982 that did not participate in the new Federal Employee Retirement System. (Interviewees, however, were not

<sup>282</sup> A separate report being submitted under this project's contract will estimate under-enrollment of AI/ANs in Medicaid, SCHIP, and Medicare for the State of Oklahoma and for individual Oklahoma counties if the data allow.

<sup>&</sup>lt;sup>281</sup> Newly-eligible Medicare beneficiaries in this region of the country receive an "Initial Enrollment Package" from CMS that contains Medicare program information according to the same schedule as other regions of the country, approximately three months before turning age 65.

able to estimate the magnitude of affected workers and the site visit team did not verify the Statement.) These individuals must apply for Medicare in person at a local SSA office. However, the interviewees reported that their local SSA office does not know whether such persons are eligible for Medicare when they turn 65 and had not yet addressed this issue at the time of the site visit.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

There was consensus among the group interviewees that there is serious under-enrollment problem in SoonerCare for Tribal members, which has increased over the past two years due to State budget shortfalls. The interviewees said that two years ago, the State heavily publicized SoonerCare especially through schools. However, these activities have been discontinued. Additionally, DHS no longer provides funds for new out-stationed eligibility workers or conducts SoonerCare training at IHS facilities due to budget problems. Interviewees from Lawton Indian Hospital said that prior to the budget cuts, they had tried twice to get an out-stationed DHS eligibility worker. Their first attempt was unsuccessful; their second effort resulted in a worker with very limited responsibilities who currently processes SoonerCare applications for children but not elders. It was also stated that communication difficulties exist between Tribal members and the out-stationed DHS employee.

Interviewees identified several barriers to AI/AN enrollment in SoonerCare in their area:

- One interviewee from the Carnegie Indian Health Clinic said that County DHS staff are sometimes unaware of third-party health insurance programs that are available (e.g., Medicare Savings Programs) and do not discuss them with clients. Additionally, a previous bad experience with County DHS staff or hearing about someone else's bad experience has discouraged some AI/ANs in their area from applying for SoonerCare.
- Interviewees said there is a fairly serious "communication gap" between Oklahoma's County DHS offices and Tribal communities in their area that interferes with Tribal and IHS staff attempts to assist individuals with program application. Several group interviewees said that when they have tried to reach their local DHS offices with questions about SoonerCare, they have not been able to talk in person with any staff.
- Poor access to SoonerCare providers and provider turnover discourages some AI/ANs from applying for the program as benefits cannot be obtained if a provider does not accept SoonerCare or the patient is unable to maintain a continuous relationship with a primary care physician who accepts SoonerCare insurance.
- According to interviewees, there is very little legal assistance available in the area for low-income people to assist with program denials. The legal assistance that is available is not widely publicized. Additionally, they said that most people will not appeal a denial due to fear of government processes and the legal system, or due to the lack of determination and endurance needed to pursue a denial.

#### Barriers to Maintaining Enrollment

There was consensus among the interviewees that SoonerCare redetermination is a very serious problem for Tribal members in their area because IHS hospital and clinic PBCs have little time to help SoonerCare recipients with the redetermination process. Primary factors identified as redetermination issues by many interviewees include:

- The failure of SoonerCare recipients to either receive their redetermination letter or to receive it in time to re-enroll in the program.
- Confusion surrounding the meaning or purpose of the redetermination letter and the actions needed for redetermination. Many recipients must talk with a DHS caseworker in person to understand the letter, often requiring transportation to the local DHS office that can be difficult to obtain.

### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Group interviewees unanimously agreed that enrollment in Medicare Part A for eligible elderly AI/ANs was not perceived to be a problem in their area because people about to turn 65 receive information "early" from CMS. However, they said that under-enrollment in Medicare Part B *is* a serious problem for Tribal members in their area, as is under-enrollment in the Medicare Savings Programs. The most serious barriers to enrollment discussed by interviewees include:

- The Medicare Part B premium is high relative to AI/AN incomes in their area and many beneficiaries are unwilling to pay the premium since they think they can obtain most Part B services through IHS facilities and/or they think needed services will be covered under Medicare Part A. Generally, interviewees said that AI/AN elderly will only enroll in Part B if they are in a crisis situation where they cannot obtain needed Part B services through other sources.
- Awareness of the Medicare Savings Programs is low among IHS hospital and clinic staff and among AI/AN Medicare beneficiaries in their area.
- Some interviewees said that elderly AI/ANs who know about the program are hesitant to enroll in the Medicare Savings Programs due to fear of losing the few assets they have after they die, such as their home and land, if the State pursues eState recovery.
- Interviewees also said that limited access to transportation is a "huge barrier" to program enrollment. However, because Medicare Savings Programs/Medicaid enrollment can be done through the mail or on-line, it is not clear why this is an enrollment barrier. Interviewees said it probably results from a lack of awareness among consumers and health care staff about these alternative application options, as well as little access to the Internet and feelings of being uncomfortable filling out printed forms on their own.

#### Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

Train all staff and providers to check for third-party insurance eligibility at all points of a patient's clinical encounters. Lawton Indian Hospital interviewees said the hospital has no formal system to identify patients who are potentially eligible for SoonerCare but are not enrolled. Moreover, PBCs have very limited time to identify patients who may be eligible for SoonerCare and to help with application. The Carnegie Indian Health Clinic interviewees, however, said their small clinic has trained all staff and providers to check for third-party insurance eligibility at all points of a patient's clinical encounters. They emphasized that a "team effort" is the key to identifying and enrolling eligible patients, with physicians being an integral part of the team as patients may be most willing to listen to them.

The CHRs at the group interview said they try to take the initiative to learn about program basics (for example, the CHRs attended a one-day CHR training recently in Oklahoma City) but feel that training is too short and too infrequent. They said that CHRs are too busy with other duties to take time for self-education. Other individuals at the group interview reported that CMS has provided some Medicare training, but the amount of information provided at one time is overwhelming.

Interviewees suggested a number of potential strategies to encourage and facilitate enrollment in the public insurance programs, including:

- IHS development of an in-house outreach system in which IHS-trained outreach and application assistance workers are placed at Tribal and IHS facilities. This would prevent the entire burden of outreach, education, and application assistance falling on individual Tribal or IHS registration clerks, PBCs, or CHRs who are already overburdened.
- Develop and implement educational programs. CMS, IHS, and State cooperation to develop and implement educational programs for AI/ANs. These programs should target both consumers and health care staff and be geared particularly to IHS/Tribal systems to help elderly and qualifying disabled persons understand 1) the types of services Medicare Parts A and B cover, 2) why they should pay the Part B premium, and 3) the relationship between Medicare and private health insurance. Interviewees said that many AI/AN elderly do not even realize they have Medicare coverage. Although hospital and clinic staff try to educate patients, it requires follow-up application and information assistance for which clinic staff does not have time. Interviewees suggested that many elderly, particularly at the Anadarko clinic where SSA does not conduct training or informational presentations, also need someone to accompany them to the SSA office to help them understand the information. One interviewee suggested that Elder Centers located in Tribal areas would be a good place for patient education because many AI/AN elders eat lunch there.
- More educational materials. The State DHS and CMS could provide more educational materials about the benefits and applications process for the Medicare Savings Programs to AI/AN Medicare beneficiaries and IHS hospital and clinic staff. Many of the group interviewees said that staff awareness of the programs is very low and that they had never

seen any publications about the programs.<sup>283</sup> Interviewees suggested that videos be used in clinic waiting rooms to reach AI/ANs which are better than reading materials due to widespread illiteracy problems.

- Actively publicize SoonerCare enrollees' choice between IHS or Tribal provider as their primary care physician. The State DHS, as well as IHS and Tribal facilities throughout the State, could more actively publicize that, since July 2001, AI/ANs enrolled in SoonerCare can choose an IHS or Tribal provider as their primary care physician. Interviewees said that many County DHS workers, as well as IHS hospital and clinic staff and CHRs, are not aware of this change. (In fact, many of the group interviewees were not aware of this.) Greater awareness would motivate some SoonerCare-eligible AI/ANs who want to maintain a medical relationship with an IHS or Tribal provider to enroll.
- Simplify the language in the SoonerCare redetermination letter. The State DHS should simplify the language in the SoonerCare redetermination letter so recipients with no more than a fourth-grade education could understand the actions redetermination requires on the part of the recipient.
- The State DHS could more actively publicize each County's DHS toll-free number.
- **Tribes could include** SoonerCare and Medicare Savings Programs applications with Tribal enrollment forms.

# Other Issues

Those attending the group interview perceive that State/Tribal relations are primarily at the IHS Area level while being "virtually non-existent at the IHS Service Unit level." They said Tribes in the Lawton Service Unit have "no relationship with the State's OHCA Tribal Liaison." They further believe that the State "has no formal mechanism for taking account of Tribal/IHS concerns."

#### FINDINGS: IHS CONTRACTING/COMPACTING TRIBES

#### Overview

Subsequent to site visit selections for Oklahoma based on recommendations described in the introduction to this report, the Tribal Liaison for OHCA expressed concern that our selections did not include any Oklahoma Tribes that operated all of the health facilities in their Service Unit under IHS compact/contract.<sup>284</sup> To address her concern, we agreed to meet with Tribal health directors from several of the compacting/contracting Tribes in a joint meeting at OHCA offices in Oklahoma City. Due to inclement weather, however, the Tribal health directors

<sup>&</sup>lt;sup>283</sup> One particular question about the Medicare Savings Programs asked by interviewees during the group meeting concerned the types of resources (e.g., Tribal land holdings) that might cause someone to be ineligible for the Medicare Savings Programs.

<sup>&</sup>lt;sup>284</sup> Although Cherokee Nation operates most of the health facilities in their area, the IHS directly operates W.W. Hastings Indian Hospital in the Tahlequah Service Unit.

were not able to attend the meeting. Instead, we agreed to conduct follow-up calls with them on an individual basis, completing interviews with representatives from Choctaw Nation, Citizen Potawatomie Nation, and Chickasaw Nation. <sup>285</sup>

Choctaw Nation. We interviewed Teresa Jackson, Business Office, Choctaw Nation Health Service Authority, by telephone soon after our site visit. Since February 1, 1985, the Choctaw Nation under the Indian Self-Determination Act has managed all health care facilities within the Talihina Service Unit in southeastern Oklahoma. The Choctaw Nation Health Service Authority operates one hospital at Talihina (Choctaw Nation Health Care Center), four comprehensive health centers, the Choctaw Nation Diabetes Treatment Center, and a telemedicine network over a State communications system to three remote sites.

The Choctaw Nation representative said very few Tribal members who are eligible for SoonerCare or Medicare Part B do not enroll. In addition to having DHS eligibility workers on site, Contract Health Services mandates that AI/ANs who need their services must first show proof of application to SoonerCare. Additionally, Choctaw Nation providers were certified as SoonerCare PCPs about a year and a half ago, "which is working well." The few Tribal members who refuse to enroll in SoonerCare say it is because they believe they are entitled to health care from the Federal government without having to go through any application process. SoonerCare redetermination is not a large problem as the Choctaw Nation's hospital and clinics flag the redetermination date in their computer systems to remind people when it is time to re-enroll.

About a year ago, DHS partnered with Choctaw Nation to out-station a DHS eligibility worker in the Nation's hospital and one at each of its satellite clinics. In fact, Choctaw Nation has a SoonerCare office located immediately adjacent to their hospital. DHS pays half of the eligibility workers' salaries and provides computers and training; Choctaw Nation pays the other half of salaries and provides office space. According to the Choctaw Nation interviewee, the outstationed workers have substantially increased Medicaid enrollment and third-party revenue. She said this is primarily because AI/ANs in the area "no longer need to go to their County DHS office to obtain the short form and the out-stationed eligibility workers are able to assist most individuals with SoonerCare applications."

Choctaw Nation health staff are concerned they may lose their out-stationed workers due to Oklahoma's budget shortfalls and have discussed possible alternatives with OHCA should this occur. In particular, they have discussed the possibility of negotiating with OHCA for the Tribe to fund 75 percent of out-stationed workers' salaries in order to maintain the Tribe's current level of third-party revenues.

Citizen Potawatomi Nation. We interviewed Bill Thorne, Director of Health Services, Citizen Potawatomi Nation and Director of Citizen Potawatomi Nation Health Center, by telephone soon after our site visit. The Citizen Potawatomi Nation Health Complex, funded from IHS compact funds and Tribal enterprise revenues, and operated by Citizen Potawatomi Nation, provides medical services to Tribal members and other AI/ANs in its service area. Because

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<sup>&</sup>lt;sup>285</sup> In addition to the Tribal health directors interviewed, site visit staff also attempted to set up a telephone interview with a Tribal health representative from the Perkins Family Clinic operated by the Iowa tribe in Oklahoma, as Ms. Terry recommended, but were unsuccessful in doing so after repeated contact attempts.

Oklahoma has no State-sponsored pharmacy assistance program, the Citizen Potawatomi Nation Health Complex's pharmacy program covers the majority of prescription drug needs for Tribal members according to the interviewee. Their pharmacy program is funded through IHS compact funds and Tribal enterprise revenues. Health Complex staff refers AI/AN patients to Carl Albert Indian Health Facility in the Ada Service Unit or other private hospitals in the area. The Citizen Potawatomi Nation also operates the Health Aid Foundation. The Foundation provides financial assistance of up to \$750 per year to Tribal members to cover durable medical equipment not available through the Tribal health system and not covered by third-party insurance.

According to the Citizen Potawatomi Nation representative, their clinic has strong third-party billings. He said when the Tribe began compacting with IHS, the clinic made third-party billings a priority, emphasizing complete, legible, and accurate medical chart documentation supported through external auditing and establishment of standards, hiring of well-trained coders, implementation of a good computer system, and contracting with external software firms to improve their RPMS-based billing and encounter system on an ongoing basis. The clinic has had trouble keeping its RPMS system current with IHS changes, although the representative said it typically takes IHS two to two-and-a-half years to make small program changes. As with Choctaw Nation, another strategy that Citizen Potawatomi Nation uses to increase SoonerCare enrollment is to require proof of program application from AI/ANs who need Contract Health Services. He feels the clinic has been able to set up the infrastructure to support strong third-party revenues because the clinic is a relatively large facility that serves a large Tribe and is supported with "good Tribal resources."

Despite strong third-party billings (mainly from private insurance according to the interviewee), the interviewee believes that under-enrollment in SoonerCare is a large problem for Tribal members. While awareness of the program is high, quite a few AI/ANs do not want to enroll because of welfare stigma, transportation problems (although he said these are not widespread), misperception about the need to enroll since they receive most of their health services free at the Citizen Potawatomi Nation clinic, and/or lack of providers who will accept SoonerCare insured patients. Generally, he said that Tribal members only enroll in or re-certify for SoonerCare when they have a specific medical need that cannot be met at the clinic and the person's resources cannot cover the cost of the needed services (i.e., when a "medical crisis" occurs). The interviewee believes that Medicare Part B under-enrollment is low for Tribal members (the main barrier for a few is inability or lack of desire to pay the premium), but is higher in the Medicare Savings Programs because the Health Complex offers a prescription drug program.

In sharp contrast to many of our interviews with representatives from other Oklahoma and non-Oklahoma Tribes, the Citizen Potawatomi Nation representative recommended that all AI/ANs should have some level of co-payment for all IHS- or Tribally-provided medical services. He believes this would promote greater patient awareness of the cost of medical care, increasing patient responsibility and sense of having some equity in their health care system, as well as provide incentives for AI/ANs to apply for third-party insurance coverage. However, he believes the decision whether or not to charge co-payments should be decided upon by individual Tribal governments.

Chickasaw Nation. We interviewed Teresa Dunn, Business Office Manager, Carl Albert Indian Hospital, Chickasaw Nation, by telephone soon after our site visit. The Chickasaw Nation operates three health centers under the Indian Self-Determination Act within the boundaries of the Ada Service Unit in south central Oklahoma: Tishomingo, Ardmore, and Durant Health Centers. The Chickasaw Nation also operates the 53-bed Carl Albert Indian Hospital at Ada. Teresa Dunn manages the patient benefit coordinators (PBCs) and oversees out-stationed DHS workers physically located at the hospital. Chickasaw Nation shares half of the cost of the outstationed workers with DHS paying the other half. She said that the on-site workers have been a significant factor for increasing SoonerCare and Medicare Savings Programs enrollment and revenues.

The Chickasaw Nation interviewee reported that SoonerCare and Medicare Part B underenrollment is a serious problem among Tribal members. She described a number of reasons that AI/ANs in the area do not want to apply, several arising from the County DHS system, lack of public awareness about eligibility requirements, insufficient program training for Tribal health care and other staff, low SoonerCare provider payment rates, Part B premiums, and fear of losing personal assets upon program enrollment. When asked about Tribal member enrollment in the Medicare Savings Programs, the Chickasaw Nation interviewee said she is not too familiar with these programs and is "under the impression that the State Medicaid office either no longer financially supports these programs or is in the process of phasing out these programs."

The Chickasaw Nation business office manager provided several recommendations for increasing enrollment in public health insurance programs, as well as for improving patient access to health services, that mainly focused on increased Tribal health staff training about the programs, increased consumer education efforts, and additional funds to provide more one-on-one application assistance to Tribal members.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

Choctaw Nation. The Choctaw Nation representative said very few Tribal members eligible for SoonerCare fail to enroll. In addition to having DHS eligibility workers on site, Contract Health Services mandates that AI/ANs must first show proof of application to SoonerCare. Additionally, Choctaw Nation providers were certified as SoonerCare PCPs about a year and a half ago, "which is working well." The few Tribal members who refuse to enroll in SoonerCare say they believe they are entitled to health care from the Federal government without having to go through any application process.

Citizen Potawatomi Nation. The Citizen Potawatomi Nation representative said that under-enrollment in SoonerCare is a large problem for Tribal members. While awareness of the program is high, quite a few AI/ANs do not want to enroll because of welfare stigma, transportation problems (although he said these are not widespread), and/or not understanding the need to enroll because they receive most of their health services free at the Citizen Potawatomi Nation clinic. In particular, he said that some AI/ANs eligible for the SCHIP portion of the SoonerCare program – "the working poor" according to the interviewee – are too proud to sign up for a public program, although he believes the stigma has been reduced over the past

three years due to effective State outreach messages to counter this perception. The interviewee also observed that a frequent barrier to enrollment is people's (AI/AN and non-AI/AN) nervousness about publicly disclosing personal information, particularly income, to a government agency. Generally, he said that Tribal members only enroll in SoonerCare when they have a specific medical need that cannot be met at the clinic and the person's resources cannot cover the cost of the services. He said he has not heard negative feedback about the SoonerCare application process.

The interviewee noted that overall third-party revenues at the clinic are strong despite SoonerCare program under-enrollment, so they do not "make a big push to enroll all eligible AI/ANs in the SoonerCare program." The clinic is located near an urban area where he said staff is fairly aggressive about screening for private third-party insurance. The interviewee also noted that patient and clinic staff incentives to enroll in SoonerCare are mitigated by the fact that very few physicians in the area accept SoonerCare patients because of the program's low provider payment rates. Clinic staff does not assist patients with the application or redetermination process. Nor does the clinic conduct outreach with Tribal members through mailings as "too much mail is returned."

As with Choctaw Nation, however, Citizen Potawatomi Nation does encourage SoonerCare enrollment for AI/ANs who need Contract Health Services. Clinic intake workers are trained to screen patients for third-party coverage or proof of application; no Contract Health Services payments are made for a patient until he/she presents screening results.

*Chickasaw Nation*. The Chickasaw Nation interviewee believes that SoonerCare underenrollment is a serious problem among Tribal members. She described a number of reasons that area AI/ANs do not want to apply:

- Perceived discrimination and negative attitudes by DHS workers at County DHS offices toward area AI/ANs discourage many from applying. Additionally, some Tribal members have reported encounters with DHS workers who encouraged them *not* to sign up for SoonerCare, implying that "they would be wasting the State's money to sign up for a State funded program when they already have access to IHS facilities." The interviewee believes that other possible reasons a DHS worker might discourage application may be a lack of understanding of the programs or how the IHS system interacts with Medicaid/SCHIP.
- Fear of the perceived requirement that their royalty checks or sacred land must be relinquished in return for SoonerCare services, as well as the unfounded belief that SoonerCare eligibility will result in their inability to receive services from Tribal or IHS facilities.
- Widespread lack of knowledge and awareness of the public insurance programs. In particular, working AI/AN families sometimes think their incomes are too high for SoonerCare eligibility.
- Instability in the DHS system. For example, in the past few years DHS has spent a great deal of money on a marketing campaign for its services but has then reduced services at

the end of each year due to budget cutbacks. According to the interviewee, this instability reduces incentives for patients to enroll in SoonerCare and Tribal health facilities to encourage such enrollment.

- Shrinking Medicaid budgets. Because SoonerCare reimbursement rates are so low, many providers will no longer accept SoonerCare patients. It is sometimes nearly impossible to locate even one provider in the State who is willing to accept a patient with Oklahoma SoonerCare coverage.
- Lack of program training by the State or other entities, and no State outreach fund. The interviewee said the State is willing to conduct Tribal staff training once or twice a year but that training occurs at the request of the Tribe and is rarely initiated by the State. The interviewee noted that the State also seems to communicate an attitude of intolerance or lack of understanding regarding AI/AN-specific training.

#### Barriers to Maintaining Enrollment

*Choctaw Nation.* According to the Choctaw Nation representative, SoonerCare redetermination is not a large problem as the Choctaw Nation's hospital as clinics flag the redetermination date in their computer systems to remind people when it is time to re-enroll.

Citizen Potawatomi Nation. The Citizen Potawatomi Nation representative said, "[A] number of Tribal members let their SoonerCare redetermination expire until the next crisis." He observed that patients with chronic medical problems are more likely to re-certify than those with episodic medical needs.

*Chickasaw Nation*. The Chickasaw Nation representative noted that the "required three-month Medicaid redetermination is a significant problem." She said that DHS workers mail redetermination materials to individuals but if an individual does not take action, they are generally cut off from benefits. She did not know why some fail to take action.

#### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Choctaw Nation. The Choctaw Nation representative said that under-enrollment in Medicare Part A is not a problem for Tribal members. There is a small under-enrollment problem for Medicare Part B because some AI/ANs do not want to pay the monthly Part B premium when they can receive care free at a Tribal clinic. Choctaw Nation clinic staff flag patients who do not have Part A or Part B and work with them to obtain it. However, the interviewee admitted that the Tribal clinics are not "at all aggressive in increasing Medicare enrollment" and do no systematic screening for the Medicare Savings Programs.

Citizen Potawatomi Nation. The Citizen Potawatomi Nation representative believes there is little under-enrollment in Medicare Part A among Tribal members. He said there is some, but not large, under-enrollment in Medicare Part B primarily due to "economics." Although he stated that most Tribal members are aware of the program, several do not want to pay the Part B

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<sup>&</sup>lt;sup>286</sup> The SoonerCare program actually requires redetermination every six months.

premium. The representative said that AI/AN elders' inability to pay co-payments and premiums is becoming an increasing problem, however, as the Tribal clinics try to boost Medicare third-party billings. The Tribe finds that it is often cheaper for it to pay the Medicare Part B premiums, co-payments, and deductibles for Tribal members who are having financial difficulty out of unrestricted clinic funds derived from private third-party payers.

The interviewee said that because elderly AI/ANs with Medicare are likely to be chronic users of health services, having medical coverage through Medicare and/or Medicaid is often a priority making them more likely than younger people to enroll in these programs. However, he said that Citizen Potawatomi Nation clinic patients have less incentive to sign up for the Medicare Savings Programs than non-users because the Tribal clinic has a prescription drug program. However, clinic staff does encourage patients to enroll in SoonerCare and/or the Medicare Savings Programs if they need referral services outside of the clinic. The representative said in general, however, that third-party revenues at the clinic are strong so they "do not make a big push to get all eligible AI/ANs enrolled in SoonerCare or the Medicare Savings Programs."

Chickasaw Nation. The Chickasaw Nation interviewee said that most eligible Tribal members are enrolled in Medicare Part A because the "40 quarters work requirement for Medicare is not an issue." She said their clinics seldom encounter elderly patients who do not meet this qualification.

In contrast, she believes that under-enrollment in Medicare Part B is a serious problem for Tribal members for a variety of reasons. First, Tribal members know that they can come to an IHS facility so they do not feel obligated to enroll. Second, the cost of the Part B premium is prohibitive for many members. Finally, once a Tribal member discovers he/she might need the coverage to receive some benefits not available at Tribal facilities, the penalty for late initiation of Part B enrollment is a common deterrent. The interviewee said that the Tribe has considered reimbursing the Part B premium to Tribal members but this is a complicated issue because there are border and boundary issues (i.e., many non-Chickasaws come to the facility for services, and there are different Service Units even for Chickasaw members).

When asked about Tribal member enrollment in the Medicare Savings Programs, the Chickasaw Nation interviewee said she is not too familiar with these programs and that she is "under the impression that the State either no longer financially supports these programs or is in the process of phasing out these programs."

# Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

Choctaw Nation. The Choctaw Nation representative said they conduct few Tribal outreach activities for SoonerCare. Health care staff does attend some AI/AN health fairs where they provide applications, but do not attend other Tribal activities or conduct outreach at area schools. The representative said she was not aware of any State outreach activities for SoonerCare or the Medicare Savings Programs.

Citizen Potawatomi Nation. In sharp contrast to many of our interviews with representatives from other Oklahoma and non-Oklahoma Tribes, the Citizen Potawatomi Nation representative recommended that all AI/ANs should have some level of co-payment for all IHS-

or Tribally-provided medical services. He believes this would promote greater patient awareness of the cost of medical care, increasing patient responsibility and sense of having some equity in their health care system, as well as provide incentives for AI/ANs to apply for third-party insurance coverage. However, he believes the decision whether or not to charge co-payments should be decided upon by individual Tribal governments.

Chickasaw Nation. The Chickasaw Nation hospital's business office manager said the Tribe provides transportation services through CHRs for Tribal members to access medical services and apply for public benefits programs. The clinic has trained CHR transportation drivers to ask clients if they are enrolled in SoonerCare, Medicare, and other public benefits programs and to give out application forms upon request. The Tribal health service's staff does not provide applications directly to people in the community, however. At the clinics and hospital, PBCs review patients' charts for evidence of third-party insurance coverage prior to a scheduled appointment. If there is no evidence of this, PBCs note this on the chart for the registration clerk to screen the patient. The PBCs also visit patients in-person at the clinics and hospital to discuss the benefits of public insurance programs and encourage application. The interviewee said that this strategy works to some extent, but while PBC staff can encourage patients to sign up for programs, they cannot deny services if a patient refuses to complete program screening or application. However, she said that Tribal member access to Contract Health Services does require third-party insurance eligibility screening. Patients are also required to apply for programs and show proof of denial to receive CHS funds.

The interviewee provided several recommendations for increasing enrollment in public health insurance programs, as well as for increasing patient access to health services:

- Better signage at Tribal and IHS clinics, patient mailings about all of the public insurance programs, and Medicare information flyers that CMS could provide to clinics would be helpful. Additionally, the interviewee suggested that funds to establish a "central benefits office" as a "one-stop shop" at each clinic or at another place central to Tribal members would help patients to access information about these programs.
- Increased funding to hire individuals who could provide one-on-one application and redetermination assistance to eligible Tribal members.
- Increased Tribal staff training from the State regarding SoonerCare eligibility issues, yearly training with IHS, and out-stationing of more DHS outreach and eligibility workers at Tribal and IHS clinics.
- Review of the construct of the County-based DHS system. The Chickasaw Nation's Tribal service unit encompasses 10 different counties and 10 different County DHS offices, all of which are run differently according to the interviewee. Additionally, while the Tribe would like to have a DHS eligibility worker out-stationed at each of their satellite clinics, according to DHS rules each individual County cannot justify a caseload to warrant this. The Chickasaw Nation representative said that if the caseload of all three counties for an out-stationed worker could be combined, the combined caseload would justify funding of such a worker.

#### Other Issues

Choctaw Nation. The Choctaw Nation representative said the only real problem the Tribe is currently experiencing with Medicaid is contracting with neighboring State Medicaid offices to allow the Choctaw Tribe to bill for services delivered to Choctaw Tribal members who live in the neighboring States but cross the Oklahoma border to receive services at Choctaw Nation clinics. Choctaw Nation has been working with Arkansas for over a year to resolve this issue but has had many problems with their reciprocal billing application. Additionally, Choctaw Nation has unsuccessfully sought Medicaid/SCHIP training from the State of Arkansas, where the interviewee said communications have been difficult. Following successful application with Arkansas, Choctaw Nation will apply to Texas for the same contractual reciprocal agreement. The Choctaw Nation interviewee said this is a large issue as they see many cross-border patients at their border health clinics. 288

A relatively small problem the Choctaw Nation interviewee discussed was caused by SoonerCare's switch to a new system that assigned new patient numbers, which patients often forget to bring to the clinics. Choctaw Nation has requested OHCA to help them establish a computerized system to link the old and new patient numbers to assist them with third-party billing.

Chickasaw Nation: The Chickasaw Nation interviewee expressed the opinion that national legislation ensuring that all Medicaid programs are administered similarly by all States would be helpful to ease the administrative issues that many health facilities face. Currently, facilities situated near State borders must deal with several Medicaid agencies with differing eligibility and payment rules.

It was also her opinion that the AI/AN population in Oklahoma does not have enough of a voice in SoonerCare policy changes, and that an authority higher than the State government is needed to address cross-border issues and over-arching AI/AN policy issues.

She also recommended that "better communication channels," such as establishment of "a task force," be created to improve information sharing between Oklahoma Tribes and the State, particularly, and with Federal government agencies. She said that although OHCA or DHS will send letters to Tribes notifying them of planned major policy changes to SoonerCare, and the State has made an effort to consult with Tribes through one individual from State government (i.e., the OHCA Tribal Liaison who is helpful when consulted), the interviewee feels these activities do not represent a substantial effort at achieving a real Tribal consultation process. She commented that even the out-stationed DHS eligibility workers at Chickasaw Nation are dissatisfied with the State because of the lack of communication with regard to policy and program changes that affect AI/ANs. While she noted the existence of a Tribal consortium in Oklahoma (the Oklahoma Indian Affairs Tribal Commission), she believes that there is not frequent enough communication between the Tribe and the Commission to facilitate an adequate flow of information to the Tribes.

<sup>&</sup>lt;sup>287</sup> She mentioned that Cherokee Nation has experienced similar problems.

<sup>&</sup>lt;sup>288</sup> W.W. Hastings Hospital staff interviewed said the IHS hospital currently has a contract with the Arkansas Medicaid agency and is working on contracts with Texas Medicaid.

#### FINDINGS: TULSA URBAN AREA AI/ANs

## Overview

At the Indian Health Care Resource Center of Tulsa (IHCRC), the site visit team met with Dianne Hughes, Clinic Administrator, and Saundra Arnold, Eligibility Coordinator for the Center and Counselor for the Oklahoma Senior Health Insurance Counseling Program (SHICP) and for Oklahoma's State Health Insurance Assistance Program (SHIP). Carmelita Skeeter, IHCRC's Executive Director, was initially scheduled to join the meeting but other time commitments ultimately did not permit her to participate.

IHCRC staff said it considers under-enrollment in SoonerCare, Medicare Part B, and the Medicare Savings Programs to be a serious problem for AI/ANs who live in the Tulsa urban area. Interviewees noted that under-enrollment in these programs has been exacerbated by the current reduction in DHS funding for out-stationed eligibility workers at IHS and Tribal clinics. Interviewees cited many of the same barriers to enrollment as Tribal interviewees: low program awareness, welfare stigma, lack of perceived need for health care coverage outside of the IHS/Tribal/Urban Indian system, inability to pay the Part B premium, fear of sharing of application information with State child support enforcement staff, fear of losing personal assets upon program enrollment, and government mistrust. A unique barrier in Tulsa – because SoonerCare recipients in the Tulsa urban area must enroll in a health plan and select a PCP – concerns reported misinformation from County DHS offices and the SoonerCare enrollment broker about managed care exceptions that pertain uniquely to AI/AN populations.

IHCRC interviewees made a number of suggestions to increase enrollment in these programs, that, again similar to Tribal interviews, focused on health facility staff program training, consumer education, increased funding for health facility staff to provide one-to-one application assistance, and simplifying both the program application processes and impediments to accessing care financed through Medicaid, Medicare, and SCHIP programs.

## Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

IHCRC's staff said they consider under-enrollment in SoonerCare to be a serious problem for AI/ANs who live in the urban area surrounding Tulsa. Five years ago, DHS funded an out-stationed eligibility worker at the local SSA office but the funding has since been cut. This worker informed Medicare beneficiaries of the SoonerCare and Medicare Savings Programs and assisted with enrollment. The patient registration desk at IHCRC does not "formally" screen for third-party resources, although Saundra Arnold, the IHCRC's Eligibility Coordinator, does work closely with patient registration clerks to help them understand details of the programs and educate potential eligible patients about the programs' benefits when they have the time.

#### Barriers to Initial Enrollment

IHCRC's interviewees reported the following barriers to initial enrollment in Medicaid as being the most significant in their opinion:

<sup>&</sup>lt;sup>289</sup> Collection of data regarding reduction in DHS funding was beyond of the scope of work for this project.

- Low awareness of the SoonerCare program itself and its benefits among urban AI/ANs. IHCRC's interviewees believe that current State media efforts are not reaching AI/ANs in either urban or Tribal areas (although they have not verified this with the State), primarily because there is no AI/AN-specific outreach.
- The belief that a welfare stigma is associated with SoonerCare enrollment.
- The view that SoonerCare coverage is not needed because they can obtain many services free at IHCRC.
- County DHS offices misinforming Tribal members that they do not need Medicaid coverage because they have access to IHS and Tribal facilities. Additionally, Oklahoma's SoonerCare HMO enrollment brokers are often misinformed about an AI/AN individual's ability to receive services from Tribal, urban Indian, or IHS providers even if enrolled in an HMO. Staff said this often causes SoonerCare enrollment to be less desirable for AI/ANs who want to continue to see these types of providers.
- The perception that many AI/AN patients "need a lot of hand-holding" to complete the application process, which neither clinic staff nor any other personnel or facilities in the Tulsa area are able to provide.
- Concern among AI/ANs that SoonerCare application will cause the State to pursue their child's absent parent for child support and "get the boyfriend or husband in trouble."
- "Trust issues" among some AI/ANs with all levels of government resulting in a reticence to disclose personal information to DHS on an application.
- The IHCRC's lack of contractual arrangements with many of SoonerCare Plus HMOs. The State reimburses IHCRC for SoonerCare services to AI/AN patients on a fee-for-service basis. However, if an AI/AN patient requires a referral outside of IHCRC, the SoonerCare Plus enrollee must first obtain a referral from his/her HMO. Some patients enrolled in HMOs with which IHCRC has not contracted are reluctant to obtain such a referral or have difficulty obtaining transportation to the HMO for the referral, and therefore, either do not enroll in SoonerCare or do not re-certify.

#### Barriers to Maintaining Enrollment

- IHCRC's interviewees said that the six-month SoonerCare redetermination process seems to be particularly problematic for pregnant woman and special needs patients. Because IHCRC's patients tend to be highly transient, however, it is difficult for center staff to follow-up with patients who do not re-certify on their own. A DHS eligibility worker used to visit IHCRC on a regular basis and could quickly re-certify people. However, DHS no longer funds this worker.
- The Center's interviewees also said that sometimes when one family member is dropped from SoonerCare, all family members are erroneously disenrolled.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

IHCRC interviewees said that under-enrollment in Medicare Part B and the Medicare Savings Programs is a substantial problem for AI/ANs who live in the urban areas surrounding Tulsa for the following reasons:

- Some do not want to pay the Part B premium, either because they cannot afford it or they do not see why they should pay it given their access to health services through the IHCRC.
- There is some welfare stigma associated with enrollment in the Medicare Savings Programs because they are administered through the State's Medicaid office.
- Concern that the State will pursue eState recovery after the beneficiary's death causes some AI/ANs not to enroll in the Medicare Savings Programs.

## Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

IHCRC staff said they currently conduct limited program outreach and education at health fairs and other community forums. Interviewees also said they refer AI/ANs with legal problems such as program denials to Attorneys for Eastern Oklahoma for assistance (a very good non-profit resource in their opinion). Additionally, IHCRC provides limited transportation for IHCRC patients referred outside of the Center using IHS vans when available. In contrast to many Reservation areas, they said no CHR transportation services are available at the Center.

To increase program enrollment, IHCRC interviewees suggested the following additional strategies:

- Re-certify all family members for SoonerCare simultaneously and require 12-month rather than 6-month redetermination. The 21-page redetermination form should also be simplified.
- Reduce enrollment time in a SoonerCare Plus HMO plan for newly eligible recipients, which interviewees said now takes two to three months. It is their view that anything that reduces "the complications of accessing the health care system, the more likely AI/ANs (and others) will be to enroll in the program." This would include simplifying enrollment processes and coordinating benefits across IHS, Tribal, urban Indian, Federal, State, and County health care systems.
- Closer cooperation. Encourage closer cooperation between County DHS offices and local Social Security offices, particularly in conducting Part B Medicare education.
- Provision of 100 percent funding by the State DHS for an out-stationed eligibility worker at IHCRC. IHCRC has discussed shared funding but determined that the increase in third-party revenues would not offset at 50-50 percent funding scheme at this time.

- **Advocacy** for enrollment in third-party programs through Tribal newsletters that describe program benefits to individuals and Tribes. Educational information could also be provided at Pow-Wows.
- **Development of easy-to-understand educational or program-related materials** using culturally sensitive designs, words, and messages. Visual and oral communication methods work best with AI/ANs.
- **Distribution of a city-wide/State-wide book of public benefits programs.** Provision of a city-wide/State-wide book of public benefits programs that would be distributed to many types of community-based organizations and health care facilities to increase awareness of the SoonerCare, Medicare, Medicare Savings Programs, and other public benefits programs.
- Training and cooperation with State. Provision by the State DHS of more SoonerCare program training at community meetings; closer cooperation between the State and local SHIP programs in providing urban area and Tribal area staff training (to SHIP staff, health facility staff, and community-based organizations); and State attendance at Senior Services meetings.

#### **DISCUSSION**

The State of Oklahoma has a history of "mixed" government-to-government relationships with AI/AN Tribes living within its borders. The AI/AN interviewees with whom the project team met suggest that this is still the case. Several Tribal representatives are clearly cognizant of the positive role the State has played in increasing Medicaid and SCHIP AI/AN enrollment across the State (most visibly perhaps by working cooperatively with many Tribal and IHS facilities to secure funding for out-stationing of DHS eligibility workers). However, other Tribal representatives expressed considerable concern that the State has not been active enough in pursuing Tribal consultation, providing SoonerCare program training, and targeting program outreach to local AI/AN communities. For example, Tribal staff and members attending the group interview at Lawton Indian Hospital perceive that State/Tribal relations are conducted primarily at the IHS Area level but are virtually non-existent at the IHS Service Unit level. They said that Tribes in the Lawton Service Unit have virtually no relationship with the State's OHCA Tribal Liaison. One interviewee at another location also mentioned that, because the OHCA Tribal Liaison is a State employee, one can never be sure whose interests she is representing – Tribes or the State. However, the interviewee was also quick to point out that this is probably the case in any State and is not a personal reflection on the Tribal Liaison, who has responded positively to requests for information and assistance.

From the State's perspective, OHCA representatives readily agreed that the State's budget shortfalls in the past two years have markedly hampered its ability to respond to AI/AN concerns, and that under-enrollment among SoonerCare eligible AI/ANs may become more of a serious problem in the future. State interviewees feel that the State currently has a good working relationship with Tribes and with local IHS staff. However, they noted that frequent Tribal staff turnover requires constant vigilance on the State's part to maintain good communication channels, and that Tribes also have a responsibility to assertively and actively pursue State

assistance. OHCA interviewees noted that the entire burden cannot be placed on the State's shoulders, particularly in light of strict budgets for DHS out-placement and SoonerCare outreach and training for all communities across the State. On the positive side, the OHCA Tribal Liaison believes that Tribally operated facilities in Oklahoma are becoming much more assertive and pro-active at billing third parties.

With one exception, the AI/AN interviewees with whom the project team met believe that under-enrollment of AI/AN people in SoonerCare, Medicare Part B, and the Medicare Savings Programs is a significant problem in Oklahoma, and that the problem has increased over the past two years due to significant cuts in Oklahoma's State budget. The exception is Choctaw Nation, whose health system interviewee estimated that only a few eligible Oklahoma Tribal members were not enrolled in these programs. The general consensus among all interviewees, however, is that there is only small under-enrollment in Medicare Part A, even among AI/ANs living in the Tulsa urban area. Several "pockets" of under-enrollment identified include IHS and Tribal non-hospital and clinic users and "at-risk" children living with an extended family that has no legal custody of the children.

As well as presenting similar qualitative estimates of AI/AN program under-enrollment across the AI/AN interviewees, interviewees' discussions of the primary causes of under-enrollment were very similar, again even for Tulsa urban-area AI/ANs. The common barriers described encompass:

- Low SoonerCare payment rates to providers that restrict SoonerCare recipients' access to providers, lowering their incentives to enroll in the program, as well as lowering Tribal and IHS facility staff incentives to encourage AI/ANs to enroll.
- Fear of the State sharing program application information with State child support enforcement staff.
- Custody issues relating to AI/AN children living with extended families.
- Lengthy redetermination SoonerCare and Medicare Savings Programs applications (currently 21-pages) and problems with the redetermination process. (The initial SoonerCare simplified application was praised by most, although few interviewees seemed to realize application could now be made through the mail or on-line, perhaps because these are not culturally-appropriate solutions.)
- Issues with County DHS offices including perceived mistreatment by DHS County staff, provision of misinformation at times, County DHS workers' lack of program awareness (particularly the Medicare Savings Programs), and poor communication with people trying to assist AI/AN applicants.
- Fear of losing current assets after SoonerCare or Medicare Savings Programs enrollment.
- Financial inability, or resistance, to paying Part B premiums, coupled with lack of understanding of Medicare Part B benefits and importance to AI/ANs.

Urban interviewees also described several barriers unique to the SoonerCare Plus program, which is Oklahoma's managed care Medicaid program for qualified individuals living in the urban areas of Oklahoma City, Tulsa, and Lawton. Lawton area interviewees, however, did not mention any barriers arising out of required managed care plan enrollment.

The most frequently suggested strategies by interviewees for improving AI/AN enrollment in SoonerCare, Medicare Part B, and the Medicare Savings Programs in Oklahoma often reflected reinStatement of State efforts that have been negatively affected by the State's budget shortfalls. For instance, interviewees were unanimous is praising Oklahoma's DHS partial funding of out-stationed outreach and eligibility workers at several Tribal and IHS facilities across the State, calling for reinStatement of funds to continue this program. Other suggestions included reinstating (and increasing past levels) of funding for AI/AN-targeted SoonerCare outreach and health facility staff training at local levels. Other common recommendations for improving AI/AN enrollment levels also reflect requests for additional funding for activities that appear to have been successful now or in the past, most significantly increased funding for patient benefits advocates or coordinators at Tribal and IHS facilities across the State. Other proposed strategies are in response to ongoing perceived enrollment barriers, most importantly 1) the need for much greater more consumer education about program benefits and how the programs relate to the IHS/Tribal/Urban Indian system of health care, 2) greater confidentiality guarantees for SoonerCare application information, and 3) simplification of the SoonerCare redetermination form, notification letters, and process.

In sharp contrast to most of the AI/AN interviewees, State officials with whom the project team met do not believe that a significant gap exists between AI/ANs in Oklahoma who are eligible and actually enrolled in SoonerCare. State interviewees believe there is some AI/AN under-enrollment in the program, but it is not widespread. However, primary causes for underenrollment noted by the State interviewees mirror most of those discussed by the Oklahoma AI/ANs interviewed, indicating that the State is aware of many of these issues. State-cited barriers include fear of the State sharing program application information with child support enforcement staff; failure of some AI/ANs to actively select a PCP upon enrollment in SoonerCare; custody issues relating to AI/AN children living with extended families; and a lengthy redetermination application process. Moreover, OHCA interviewees also seem to be fully cognizant of how Oklahoma's budget cuts have hampered the State's past outreach and enrollment activities that seem to have been effective. The two main differences between AI/AN and State interviewee discussion of enrollment barriers concerned lack of SoonerCare providers and problems with the County DHS system, which were not brought up by the State representatives. State interviewees estimated there is some but not serious under-enrollment in the Medicare Savings Programs, although they were not sure of the causes.

The State officials the project team met suggested AI/AN enrollment strategies that often mirrored those of AI/AN representatives interviewed. Their suggested strategies for maintaining or increasing current AI/AN enrollment levels include both individual and community/Tribal level targeting of consumer education about program benefits; funding to increase staff at Tribal and IHS facilities to provide screening and one-to-one application assistance; and increased or restored funding to allow DHS outreach and eligibility worker out-placement at Tribal and IHS facilities.

# APPENDIX VIII.A: OKLAHOMA SITE VISIT CONTACT LIST

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Hospital		

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# APPENDIX VIII.B: VOLUNTARY PARTICIPATION FORM, CHEROKEE NATION

American Indian/Alaska Native Eligibility and Enrollment in Medicaid, the State Children's Health Insurance Program, and Medicare

Centers for Medicare & Medicaid Services (CMS) Contract No. 500-00-0037 (Task 5)

#### VOLUNTARY PARTICIPATION IN INFORMATIONAL INTERVIEWS

As described in the attached project description, the project team for the CMS-sponsored project entitled "American Indian/Alaska Native Eligibility and Enrollment in Medicaid, the State Children's Health Insurance Program, and Medicare," is conducting in-depth case studies in 15 States (AK, AZ, CA, MI, MN, MT, ND, NM, NY, OK, OR, SD, UT, WA, and WI) to identify enrollment barriers to Medicaid, the State Children's Health Insurance Programs (SCHIP), and Medicare. CMS is collecting this information so that it may develop new education and outreach initiatives to increase enrollment of AI/ANs in these three public health insurance programs. The case studies involve informational interviews with Tribal leaders, Tribal Health Directors and staff, IHS Area and Service Unit Medical Directors and staff, State Medicaid and SCHIP officials, Urban Health Center Directors, Community Health Representatives, Title VI directors, and Medicaid/SCHIP eligibility and outreach workers, among others.

All individuals who voluntarily agree to be interviewed in person or by phone by the project team for the case studies are under no obligation to respond to any questions asked. Individuals who choose to participate in the informational interviews will have an opportunity to respond orally or in writing – either during or after the on-site or telephone interview – to the following questions. Responses are strictly on a voluntary basis; each individual interviewed has the right to respond to any, all, or none of the questions.

CMS is very interested in hearing your perspectives and feedback on any problems American Indians and Alaska Natives may have in accessing critical health care services for low-income families and children, the elderly, and disabled persons. CMS would also very much like to know your opinions and ideas on how CMS, States, or others can best assist American Indians and Alaska Natives to access quality health care through the Medicaid, SCHIP, and Medicare programs.

## CHAPTER IX. SOUTH DAKOTA

#### **BACKGROUND**

#### Overview

This Case Study Report presents background information and findings from a four-day site visit to South Dakota conducted in Rapid City, Pierre (State Capitol), and the Rosebud and Crow Creek Reservations in South Dakota. The site visit team included Kathryn Langwell and Tom Dunn of Project HOPE and Frank Ryan, J.D., a consultant to the project. Interviews were conducted with the South Dakota Department of Social Services (DSS), the South Dakota State Tribal Liaison, DSS eligibility and enrollment staff in several locations, urban Indian health facility staff and managers, and Tribal Health Directors and staff, Indian Health Service (IHS) staff, Council members, and Tribal members on the Rosebud and Crow Creek Reservations.

An earlier version of this Draft Case Study Report was reviewed by the Centers for Medicare & Medicaid (CMS) Project Officer and by other CMS staff, for accuracy and clarity. Subsequently, the Draft Case Study Report was sent to each of the South Dakota organizations that participated in the site visit, with a request that the draft be reviewed for accuracy and that comments and additions be incorporated into the Case Study Report. Despite follow-up contacts with these organizations, no comments and corrections had been received from South Dakota site visit participants at the time that this report was finalized.

The comments and recommendations contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or the feasibility of the recommendations. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services, the Indian Health Service, or the State.

## South Dakota AI/AN Population and Location

South Dakota is bounded on the north by North Dakota; on the east by Minnesota, Iowa, and the Big Sioux and Red Rivers; on the south by Nebraska and the Missouri River; on the west by Wyoming and Montana. Within its borders<sup>290</sup>, South Dakota contains nine Federally Recognized Tribes (Table 1)—all of which fall under the jurisdiction of IHS Region VII (Aberdeen Area), as do six Tribes in North Dakota, two Tribes in Iowa, and three Tribes in Nebraska.<sup>291</sup> In 2000, there were 62,283 American Indians in South Dakota (8.3 percent of the State's aggregate population), the majority of whom live in the Western half of the State.<sup>292</sup>

The combined landmass of South Dakota's Reservations equals 45 percent of the State's total landmass of 75,885 total square miles. With a Statewide population density of only 9.9

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<sup>&</sup>lt;sup>290</sup> Standing Rock and Lake Traverse Reservations (Sisseton-Wahpeton Tribe) cross into North Dakota.

<sup>&</sup>lt;sup>291</sup> US Department of Commerce, Economic Development Administration; American Indian Reservations and Trust Areas. http://www.osec.doc.gov/eda/html/1g3 4 indianres.htm, accessed February 18, 2003.

<sup>&</sup>lt;sup>292</sup> U.S. Census Bureau, Census 2000, Profile of General Demographic Changes: 2000 (Table DP-1). Washington, DC, http://censtats.census.gov/data/South Dakota/04046.pdf.

people per square mile (51.2 percent urban and 48.8 percent rural<sup>293</sup>), much of South Dakota is classified as rural/frontier.<sup>294</sup> The geography and related travel distances between communities directly affect health services accessibility and amplifies systemic and geographic impediments for enrollment in Medicaid, SCHIP, and/or Medicare.

Table 1. Characteristics of Reservations in South Dakota<sup>295</sup>

Tribe	Reservation Population	Total Reservation Landmass	AI/AN Health Services	Geographic Location*
Cheyenne River Sioux Tribe	5,092	1.4 million acres	IHS, contract	East River
Crow Creek Sioux Tribe	1,230	123,000 acres	IHS, contract	East River
Flandreau-Santee Sioux Tribe	504	2,356 acres	IHS, contract	East River
Lower Brule Sioux Tribe	1,095	240,000 acres		West River
Pine Ridge Sioux Tribe	20,806	1.8 million acres	IHS, contract	West River
Rosebud Sioux Tribe	12,783	1.0 million acres	IHS, contract	West River
Sisseton-Wahpeton Sioux Tribe	9,894	106,153 acres	IHS, contract	East River
Standing Rock Sioux Tribe	7,956	848,000 acres	IHS, contract	West River
Yankton Sioux Tribe	6,281	435,000 acres	IHS, contract	East River

<sup>\*</sup> Indicates "east or west" of the Missouri River, which bisects the State in approximately equidistance segments

Table 2 provides data on the number and proportion of the population that is AI/AN in each of the primary counties where Reservations are located in South Dakota, ranging from 95 percent in the primary County for Pine Ridge, to 13.8 percent in the Flandreau-Santee Reservation's primary County. Median age of the Indian population is also provided in Table 2 for each Reservation. The median age on the Rosebud and Crow Creek Reservations is 21.7 years and 23.4 years, respectively, compared with a median age of the South Dakota population of 35.6 years.

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<sup>&</sup>lt;sup>293</sup> http://www.sdgreatprofits.com/South Dakota\_Profile/demographics.htm, accessed February 18, 2003.

<sup>&</sup>lt;sup>294</sup> US Census Bureau, State and County Quick Facts. http://quickfacts.census.gov/qfd/States/46000.html, accessed February 17, 2003.

<sup>&</sup>lt;sup>295</sup> US Department of Commerce, Economic Development Administration; American Indian Reservations and Trust Areas. http://www.osec.doc.gov/eda/html/1g3\_4\_indianres.htm, accessed February 17, 2003.

Table 2. Percent AI/AN Population and Median Age in Primary Reservation Counties in South Dakota, 2000

	Crow Creek	Pine Ridge	Rosebud	Cheyenne River	Lower Brule	South Dakota	US
Total AI/AN population.	1,692 (83.3%)	11,850 (95.1%)	7,861 (86.9%)	4,429 (74.2%)	1,351 (34.7%)	62,283 (8.3%)	1.5%
Median Age	23.4	30.6	21.7	26.5	34.5	35.6	35.3

Table 2. Percent AI/AN Population and Median Age in Primary Reservation Counties in South Dakota, 2000 (continued)

Dukota, 2000 (continued)						
	Lake Traverse	Standing Rock	Yankton	Flandreau -Santee	South Dakota	US
Total AI/AN population.	3,121 (31.2%)	4,503 (75.4%)	2,754 (29.5%)	909 (13.8%)	62,283 (8.3%)	1.5%
Median Age	37.1	26.5	35.7	37.0	35.6	35.3

Source: U.S. Census Bureau, Census 2000 Redistricting Data (Public Law 94-171) Summary File, Matrices PL1, PL2, PL3, and PL4.Note: Some Reservations extend over multiple counties. The data in this Table is drawn from the Reservation County that has the largest number of persons who reported AI/AN race, alone or in combination with one or more other races, on the 2000 Census. The Census Bureau had not yet released public use files providing data on Reservation populations, at the time this report was prepared, and it was not possible to construct population profiles for individual Reservations. It is anticipated that 2000 Census data on Reservation areas will be released in December 2003.

The overall number of South Dakota families with incomes below the Federal Poverty Level (FPL) has decreased since 1989. An estimated 99,871<sup>296</sup> South Dakota families had incomes below the FPL in 2000, compared to 106,305 in 1989,<sup>297</sup> constituting a 2.6 percentage point decrease in the proportion of families with incomes below the FPL over that period. During that same reporting period, the median household income in South Dakota grew from \$22,503 (1989)<sup>298</sup> to \$35,282 (1999).<sup>299</sup> However, the incomes of most AI/ANs residing on Reservations in South Dakota are substantially lower than the South Dakota average. The three poorest Reservations in the State reported an average per capita income of \$6,321 in 1999, which is 64 percent lower than the rest of South Dakota (\$17,562), and 71 percent lower than the US as a whole (\$21,587).<sup>300</sup>, <sup>301</sup> (see Table 3.)

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<sup>&</sup>lt;sup>296</sup> U.S. Census Bureau, State and County Quick Facts. http://quickfacts.census.gov/qfd/States/46000.html, accessed February 18, 2003.

<sup>&</sup>lt;sup>297</sup> U.S. Census Bureau, U.S. Bureau of the Census, 1990 Census of Population and Housing, Summary Tape File 3 (Sample Data): 1989 http://factfinder.census.gov/servlet/QTTable?\_ts=63649482510, accessed February 18, 2003.

<sup>&</sup>lt;sup>298</sup> U.S. Census Bureau, County Estimates for Median Household Income for South Dakota: Census 1989. http://www.census.gov/hhes/www/saipe/stcty/ccn 46.htm.

<sup>&</sup>lt;sup>299</sup> U.S. Census Bureau, State and County Quick Facts, http://quickfacts.census.gov/qfd/States/46000.html.

http://factfinder.census.gov/bf/\_lang=en\_vt\_name=DEC\_2000\_SF3\_U\_DP3\_geo\_id=01000US.html, accessed February 17, 2003.

U.S. Census Bureau, Census 2000 Summary File; various matrices, http://factfinder.census.gov/bf/lang=en\_vt\_name=DEC\_2000\_SF3\_U\_DP3\_geo\_id=01000US.html, accessed February 17, 2003.

Table 3. Economic Characteristics in Primary Reservation Counties in South Dakota, 1999

Table 3. Economic Characteristics in Triniary Reservation Countres in South Dakota, 1999							
	Crow Creek	Pine Ridge	Rosebud	Cheyenne River	Lower Brule	South Dakota	US
1999 Per Capita Income	\$5,213	\$6,286	\$7,714	\$7,463	\$13,862	\$17,562	
Percent Below Federal Poverty Level, 1999							
All Families	55.7%	45.1%	44.0%	45.2%	19.4%	9.3%	9.2%
Families With Children Under 18 Years	61.2%	51.8%	49.9%	55.0%	26.9%	13.9%	13.6%
Individuals aged 18-64	53.5%	45.4%	41.2%	42.1%	19.5%	11.7%	10.9%
Individuals aged 65 and older	50.4%	36.0%	33.5%	27.2%	12.9%	11.1%	9.9%

**Table 3. Economic Characteristics in Primary Reservation Counties in South Dakota**, 1999 (continued)

	Lake Traverse	Standing Rock	Yankton	Flandreau- Santee	South Dakota	US	
1999 Per Capita Income	\$13,428	\$8,615	\$11,502	\$16,541	\$17,562	\$21,587	
Percent Below Federal Poverty Level, 1999							
All Families	16.6%	32.8%	20.8%	7.3%	9.3%	9.2%	
Families With Children Under 18 Years	24.6%	41.2%	29.3%	10.7%	13.9%	13.6%	
Individuals aged 18-64	18.6%	36.6%	22.7%	8.7%	11.7%	10.9%	
Individuals aged 65 and older	17.4%	32.7%	21.0%	10.9%	11.1%	9.9%	

Source: U.S. Census Bureau, Census 2000 Redistricting Data (Public Law 94-171) Summary File, Matrices PL1, PL2, PL3, and PL4.Note: Some Reservations extend over multiple counties. The data in this Table is drawn from the Reservation County that has the largest number of persons who reported AI/AN race, alone or in combination with one or more other races, on the 2000 Census. The Census Bureau had not yet released public use files providing data on Reservation populations, at the time this report was prepared, and it was not possible to construct population profiles for individual Reservations. It is anticipated that 2000 Census data on Reservation areas will be released in December 2003.

The poor health status of the AI/AN population relative to the U.S. population as a whole has been well documented. In addition, there are also great disparities in health status among AI/AN populations. The IHS Aberdeen Area (of which South Dakota is a constituent) AI/AN population exhibits much poorer health status than the average for the rest of the nation's AI/AN population. Infant mortality rates in the Aberdeen Area are 85 percent higher than the U.S. All Races rates; death rates from cancer are 30 percent higher than the U.S. All Races rate, and the tuberculosis rate is the highest among all IHS regions. Life expectancy of the AI/AN population in the Aberdeen Area is also substantially lower. AI/AN males in the Aberdeen Area had a life expectancy of 61 years in 1994-96, compared with 73 years for all U.S. males and 70 years for all AI/AN males.

<sup>&</sup>lt;sup>302</sup> Source: T. Young, "Recent Health Trends in the Native American Population," in *Changing Numbers, Changing Needs: American Indian Demography and Public Health*, National Research Council, pp53-75; US Department of Health and Human Services, Trends in Indian Health, 1997, Indian Health Service.

<sup>&</sup>lt;sup>303</sup> U.S. DHHS, Regional Differences in Indian Health, 1997, Indian Health Service.

#### AI/AN Health Services in South Dakota

The Aberdeen Area IHS was established to serve the AI/AN Tribes in North Dakota, South Dakota, Nebraska, and Iowa. IHS brings health care to approximately 104,000 AI/ANs living in rural areas, as well as the urban AI/AN population in Rapid City, South Dakota. The Area Office's service units include nine hospitals, eight health centers, two school health stations, and several smaller health stations and satellite clinics. Beach hospital, health center, and/or satellite clinic incorporates a comprehensive health care delivery system that provides inpatient, outpatient care and/or conducts preventive and curative clinics. The Aberdeen Area also operates an active research effort through its Area Epidemiology Program. Research projects deal with diabetes, cardiovascular disease, cancer, and the application of health risk appraisals in all communities. Tribal involvement is a major objective of the program, and several Tribes have assumed management of components of their own health care programs through contractual arrangements with the IHS.

Of the 13 Service units in the Aberdeen Area, seven of them are located in South Dakota; another is just south of the North Dakota border and provides satellite "health stations" in two communities in South Dakota. The IHS operates all Service Units in South Dakota, including:

- On the Cheyenne River Reservation, IHS operates a 27-bed (recently renovated) hospital with an active outpatient clinic. It is staffed by five physicians, and is the only inpatient facility on the Reservation. The dental program is located at the hospital and includes a five-chair clinic and three off-site dental clinics. In addition, the Cheyenne River Service Unit has four satellite clinics that offer ambulatory services and are operated by the Cheyenne River Sioux Tribe with Tribal support staff.
- Although the main hospital for the Standing Rock Reservation is located at Fort Yates, ND, an outpatient health center operates in McLaughlin, SD, with one staff physician. There are also health stations at Bullhead, SD and Wakpala, SD, which provide routine outpatient care and are staffed by a physician's assistant, a public health nurse, and a community health representative. A physician from the Fort Yates IHS hospital visits these health stations at least once a week.

On the Pine Ridge Reservation, there is a new 46-bed hospital and the hospital's pharmacist, dentist, clinic nurse, a physician's assistant, and physician consultants also provide services for the nearby Health Center in Wamblee. Also located on the Pine Ridge Reservation is a health center in Kyle, South Dakota, and another health center is currently being planned for Manderson, South Dakota.

On the Rosebud Reservation, IHS is the primary source of health care for the Rosebud Sioux people. The Tribal population is spread among 20 Reservation communities, some of which lie outside the boundaries of the Reservation. A new 35-bed comprehensive medical/surgical hospital provides obstetric and pediatric services and several field clinics. It is

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http://www.ihs.gov/FacilitiesServices/AreaOffices/Aberdeen/aberdeen-origins-objectives.asp, accessed February 14, 2003.

http://www.ihs.gov/FacilitiesServices/AreaOffices/Aberdeen/, accessed February 14, 2003.

staffed by 11 physicians and is supported by physician assistants and nurse/midwives. Dental care is also offered at the new hospital.

The Sisseton Service Unit, which includes the Lake Traverse Reservation, is staffed by five-physicians and operates an 18-bed hospital with outpatient and dental clinics in Sisseton, South Dakota. The programs administered by the Sisseton-Wahpeton Tribe include an alcohol treatment program, community health, family planning, maternal and child health services.

The Crow Creek and Lower Brule Reservations have their own outpatient health center and dental clinics; two physicians staff Fort Thompson's new Health Center and two physicians and a physician's assistant staff the Health Center at Lower Brule. Emergency patients are seen after hours and on weekends at Mid-Dakota Hospital in Chamberlain, South Dakota, and inpatient care is contracted to area hospitals, the closest being Mid-Dakota.

The Wagner Health Center, on the Yankton Reservation, is an ambulatory care unit with 24-hour emergency room service. The ambulatory unit contains nine exam rooms, lab, X-ray, ENT, pharmacy, dental unit, public health nursing, mental health services, and optometry services. Obstetric care is provided by contract with the Sacred Heart Hospital in Yankton. The outpatient department serves both the Yankton and the Santee Sioux Tribes and contract specialists hold clinics at the facility. There is also a small outpatient clinic for students at the Tribal school in Marty. The Wagner Community Memorial Hospital is a 20-bed private facility with a full array of ancillary services. The hospital includes a one-day-a-week surgery program and a family clinic; two family practice physicians and one internal medicine physician staff both facilities.

#### **Overview of South Dakota State Government**

The Office of Tribal Government Relations, previously known as the Office of Indian Affairs, was established in 1949 in accordance with Statue SDCL 1-4-1. Under the direction and supervision of the Governor's Office, 306 the functions of this office are multifaceted. Specifically, the Office strives to aid in securing and coordinating Federal, State, and local resources to help resolve AI/AN issues, and to serve as an advocate for the AI/AN people. The Tribal Government Relations Mission Statement provides further insight:

"To establish and maintain an effective communication link between the Governor and the Tribal Governments in the State. To recommend qualified Native Americans to boards, commissions and positions within State Government; and to introduce and/or support any legislation that would improve the quality of life for the Native American population in the State. Identify, develop and/or coordinate Federal, State and local resources to help solve Native American problems and to serve as an advocate of the Native American population."

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<sup>&</sup>lt;sup>306</sup> The Tribal Government Relations Commissioner is appointed by the Governor.

## **South Dakota State Medicaid Program**

As of December 2002, there were 90,776 residents of South Dakota receiving benefits under Medicaid and the SCHIP Medicaid expansion (Title XIX and XXI). The South Dakota Department of Social Services (DSS) administers *Medical Assistance* programs that provide health coverage programs to eligible individuals. Table 4 summarizes the income eligibility limits for each eligibility category.

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<sup>&</sup>lt;sup>307</sup> http://www.State.sd.us/social/DSS/Stats/Med/2002/December.htm, accessed February 14, 2003.

Table 4. South Dakota Medicaid Eligibility Limits for Low Income Families

Category	Family Size	Monthly Adjusted Income	Formula			
	Family of one	\$563				
	Family of two \$703 The LIF income lim calculated by the gro					
N. 1. 1 A						
Medical Assistance for Low Income Families (LIF) <sup>308</sup>	Family of four \$885 income minus a list of					
Low meome rammes (Lif-)	Family of five \$977 specified exemptions Family of six \$1070					
	Each additional member over six, add \$90					
	Family Size	Monthly Income Limit (with	Monthly Income Limit			
	7 11 0	shelter expenses)	(Living with others)			
Full Coverage for	Family of two	\$448	\$295			
Pregnant Women <sup>309</sup>	Family of three	\$507	\$354			
	Family of four	\$563	\$412			
	Family of five	\$622	\$470			
	Family of five	\$680	\$528			
	Amount increases with each additional member					
Medicare Recipients: People 65 or older, people who are blind, people who have a disability	Income limit is based on the family size and gross income of the adults in the household. The Resource limit is \$4,000 for an individual and \$6,000 for a couple. Non-exempt resources include items such as checking/savings accounts and certificates of deposit.					
Newborns	There is no resource or income limit. The child must be born to a woman eligible for and receiving medical assistance on the date of the child's birth. Coverage is automatic from the month of birth until the end of the month in which the child turns one (1) year of age, as long as the mother continues to live in South Dakota and the child remains in her care/control.					
Family Support Services:  For children with a developmental disability, < 22 years old, living in the family home on a full-time basis  The child's monthly income must be less than 300 percent of the SSI Standard Benefit Amount (\$1,656) and resources must be less than \$2,000.310						

Source: http://www.State.sd.us/social/MedElig/index.htm, accessed February 14, 2003.

DSS employs a Primary Care Case Management (PCCM) fee-for-service model of coverage to improve eligible recipient's access to medical care, as well as improve the quality of care received by providing a medical home. At the end of January 2003, there were 70,149

<sup>&</sup>lt;sup>308</sup> For both LIF and Full Coverage for Pregnant Women, the family's household resources may not exceed \$2,000. Resources include items such as checking and savings accounts and certificates of deposit (CDs). In addition, certain assets, such as the home in which they live and one vehicle, regardless of value, are not counted. For Full Coverage for Pregnant Women only, a portion of the parents' income and resources are countable if the recipient is under age 18 and living with a parent(s).

Resources include items such as checking and savings accounts and certificates of deposit. Income and resources of the parents are not considered to determine eligibility

enrolled in Statewide-managed care programs.<sup>311</sup> The following categories of recipients are required to participate in this program:<sup>312</sup>

- Supplemental Security Income (SSI) recipients: blind, disabled people.
- Families eligible for the Low Income Families (LIF) Program.
- Low income children eligible for Medicaid or SCHIP.
- Pregnant women.

The PCCM program is not mandatory for dual-eligibles, persons in long-term care, children in foster care, and other specified categories of beneficiaries, e.g., SSI children.

The State offers Medicare Savings Programs covverage for qualified Medicare beneficiaries. The following Statement, as posted on the State's web site, promotes these programs by stating, "This program can save people up to \$704.40 each year. Many people use the extra money to help pay for living expenses or prescription drugs." In addition, the State also offers what is referred to as "Qualified Individuals-1." Beneficiaries qualified for this particular benefit receive full payment for their Medicare Part B premium only (this benefit will remain funded until April of 2003).

AI/ANs receiving Medical Assistance from one of the DSS-administered programs may continue to receive medical care from IHS facilities by selecting an IHS provider as their Primary Care Provider (PCP). AI/AN beneficiaries are also permitted to receive services from IHS without a referral from their PCP.

# **South Dakota SCHIP Program**

South Dakota's SCHIP program is designed to provide health insurance coverage to uninsured children whose family income is up to 200 percent of the Federal Poverty Level, 314 through a mixed Medicaid expansion (covering children in households with income up to 140 percent of the FPL) and a separate State Children's Health Insurance Program, Non-Medicaid (CHIP-NM, covering uninsured children with incomes above 140 percent of the FPL up to 200 percent of the FPL). As of January 2003, there were 60,930 children receiving Medical Assistance in South Dakota; 9,048 children covered under CHIP-NM, and 51,882 children covered under Medicaid. By comparison, there were 34,890 children covered under Medicaid in June 1998, prior to implementation of the SD-CHIP program. Thus, 26,040 more children are enrolled in Medical Assistance/CHIP in January 2003 than in June 1998.

http://www.State.sd.us/social/Medical/CHIP/FAQ.htm#answer3, accessed February 14, 2003.

http://www.State.sd.us/social/Medical/mcp/MC%20Enrollment/ManagedCareEnroll.htm, accessed February 14, 2003.

<sup>&</sup>lt;sup>312</sup> The "Medical Benefits ID Card," used by those enrolled in the above programs, looks like a credit card and is used for those who meet Medical Assistance eligibility criteria.

http://www.State.sd.us/social/MedElig/Medicare/index.htm, accessed February 14, 2003.

<sup>315</sup> http://www.State.sd.us/social/Medical/CHIP/FAQ.htm#answer1, accessed February 14, 2003.

In 2000, South Dakota<sup>316</sup> was awarded a grant under the initial Robert Wood Johnson Foundation *Covering Kids Initiative*.<sup>317,318</sup> This \$599,972 grant<sup>319</sup> provided Statewide training for representatives of child service agencies, service clubs, and religious and community groups to identify and enroll children into the State's health insurance coverage programs.<sup>320</sup>

Two pilot sites (one urban and the other on a Reservation) were selected to develop and test innovative outreach options. The Reservation pilot, conducted on the Cheyenne River Indian Reservation in north-central South Dakota, was designed to focus outreach efforts on two population groups with challenging enrollment requirements, i.e., isolated families in a "frontier" service area and American Indians living on the Cheyenne River Indian Reservation.

Using a three-tiered approach to outreach, volunteer workers were trained to conduct door-to-door campaigns and assist potentially eligible recipients in completing application paperwork. Second, direct outreach at local community and Tribal events was conducted to provide project staff an opportunity to communicate with potential recipients and market the program. And, third, outreach strategies were employed that used a broad-based marketing campaign to reach eligible families who have limited access to traditional media venues. 321

Assessment of the Cheyenne River pilot program identified two "best practices" strategies. First, outreach workers in the frontier pilot site exceeded expectations in application assistance and subsequent submission. Success was attributed to two interrelated factors: personal standing of the program workers within the Indian community; and willingness to provide face-to-face assistance – in the applicant's home, if necessary. Second, linking outreach and enrollment efforts to the free/reduced school lunch program was an effective intervention.

#### **DESCRIPTION OF SITE VISIT**

#### **Overview**

Prior to conducting the site visit to South Dakota, the site visit team contacted Carole Anne Heart, <sup>322</sup> Executive Director of the Aberdeen Area Tribal Chairmen's Health Board, to discuss the Tribes and Reservations within South Dakota, as well as urban AI/AN health issues and facilities. Ms. Heart provided substantial background information and recommended that we talk further with individuals at the Aberdeen Area Office of the IHS to obtain their views of the specific Reservations and urban areas that would be visited in South Dakota. Discussions were then initiated with staff at the Aberdeen Area Office of the IHS to obtain advice, background, and guidance on which communities the site visit team should visit in Minnesota, potential key contacts, and specific issues that should be addressed in the site visit. Further advice and

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<sup>&</sup>lt;sup>316</sup> Due to a State hiring freeze, the State could not take on the responsibility for the Covering Kids grant. As a result, the SD Community Healthcare Association applied for and was awarded the CK grant in South Dakota.

<sup>&</sup>lt;sup>317</sup> The *initial* Covering Kids (CK) grant should not be confused with the existing *Covering Kids and Families* grant. <sup>318</sup> The grant was administered by the Community HealthCare Association located in Sioux Falls, South Dakota.

http://www.coveringkids.org/projects/State.php3?StateID=SD, accessed February 14, 2003.

As part of this project, a Statewide coalition, consisting of a broad spectrum of advocates, works to identify barriers to accessing health care coverage and develop/implement outreach, coordination and simplification strategies to reduce enrollment barriers.

http://www.coveringkids.org/projects/pilot.php3?PilotID=128, accessed February 14, 2003.

Ms. Heart is a consultant to the project and has provided advice and information on a number of issues.

suggestions were obtained from Jim Lyon, the CMS Native American Contact for Region VIII, and from Paula Hallberg of the Community HealthCare Association (and Director, South Dakota Covering Kids Initiative). For each of these discussions, the project team initially provided the individual(s) interviewed with a copy of the project description and summarized the goals of the site visits. Interviewees were then asked to recommend two Tribes/Reservations<sup>323</sup> and one urban area with a facility that provides direct medical services and to provide background information on the sites recommended. The project team also noted that travel distances were also of importance in determining site selection.

Based on these discussions and the recommendations received, the project team selected the Rosebud Reservation in south central South Dakota (East River) and the Crow Creek Reservation in central South Dakota (East River) as visit sites. Sioux San IHS Hospital in Rapid City, SD and the Native Women's Health Center in Rapid City were selected as the urban Indian health facility visit sites. In addition, the project team also scheduled a one-day visit to Pierre, the South Dakota State capitol, to meet with State Medical Assistance and Children's Health Insurance Program staff, the Director of the Office of Tribal Government Relations, and County enrollment staff.

The process for recruiting participation in the site visit included: 1) a letter sent to the Tribal Chairmen at Crow Creek and Rosebud to inform them of the study and that their Tribe had been selected to participate; 2) follow-up telephone calls to the Tribal Chairmen to confirm their willingness to participate and to identify a coordinator from the Tribe to assist in scheduling and coordination of the site visit; 3) close coordination between the project team and the Tribal coordinator to determine the individuals who would participate in the scheduled meetings and to obtain background information on unique issues and programs at each site; and 4) development of a formal agenda for each site visit. For the Rapid City urban Indian health facilities, a similar process was followed. Project team members had worked closely with the Sioux San Indian Health Service Hospital staff on previous projects, which facilitated the scheduling and coordination of the visit to that site. A complete list of individuals who were interviewed during the site visit is provided in Appendix IX.A.

#### **Description of the Rosebud Sioux Tribe Reservation**

Located in south central South Dakota, just above the Nebraska State line, The Rosebud Reservation was established by an act of Congress on March 2, 1889. Governed by a Tribal president, Tribal council, and executive committee, Rosebud has a total Reservation population of 12,783. Total Rosebud Sioux Tribal enrollment is 15,438. Many of the Reservation's residents live in very remote areas that can only be accessed, for months at a time, by four-wheel drive vehicles. The vast size and remoteness of the Rosebud Reservation, coupled with the extreme environmental conditions in both winter and summer, make transportation a critical issue in terms of access to food, medical care, and other goods and services.

Because none of the Tribes in South Dakota manage their own health facilities under 638 contracts or self-governance compacts, it was not possible to select one Reservation with IHS direct service facilities and one with Tribally managed facilities as was the goal in other sites.

Like many Reservations in South Dakota, Rosebud Reservation is not thriving economically. The Rosebud Reservation has the second lowest per capita income among South Dakota Reservations and the lowest median age. The Bureau of Indian Affairs estimates that the unemployment rate exceeds 80 percent. Where employment does exist, many Rosebud Sioux are engaged in Tribal enterprises, ranching, or light manufacturing (e.g., electronics, gold/silver jewelry). In 1995, the Tribe opened a casino that was expected to alter the Tribal economy significantly. Rosebud Reservation is also the Home of Sinte Gleska University. The University was founded in 1971 and is a fully accredited four-year institution, conferring associates and bachelor degrees. Full-time undergraduate students for the 1999-2000 school year totaled 111.

On the Rosebud Reservation, IHS is the primary source of health care for the Rosebud Sioux people. The Tribal population is spread among 20 Reservation communities, some of which lie outside the boundaries of the Reservation. A new 35-bed comprehensive medical/surgical hospital provides obstetric and pediatric services and is staffed by 11 physicians, physician assistants, and, nurse/midwives. Dental care is also offered at the new hospital.

The lack of affordable and adequate housing among the Sioux people in South Dakota continues to be a major political, health, and socioeconomic issue. The American Indian Relief Council reported that, "In treaties negotiated with the Sioux Tribes, the U.S. government promised, in exchange for land, to adequately house each Sioux family"; however, this contractual obligation has often failed to materialize. 326

#### **Description of the Crow Creek Sioux Tribe Reservation**

The Great Sioux Reservation, created under the Fort Laramie Treaty of 1868, was reduced to about one-tenth its size in 1889, due to white settlement on Indian land within the confines of the Reservation. The Crow Creek Reservation was one of three smaller Reservations created as a result of this incursion. As Sioux families were randomly assigned to live on the Crow Creek Reservation, many extended families were split up – an action that imposed significant cultural, religious, and socioeconomic hardships.

Located mid-State and just east of the Missouri river, the Crow Creek Reservation is subject to temperature extremes in both winter and summer. Harsh weather conditions, travel distances, and lack of reliable transportation make travel, to acquire the necessities of life, an everyday challenge for many residents of the Reservation. In winter, ambulances sometimes are even used to deliver food and medicine to elderly people on the Reservation.

Approximately 1,230 persons live within the Crow Creek Reservation borders, with an additional 500 individuals residing in close proximity to the Reservation. Median age of the Reservation population is 23.4 years. Socioeconomic circumstances for the Crow Creek

<sup>324</sup> Sinte Gleska University home page: http://www.universities.com/Schools/S/www.Sinte\_Gleska\_University.asp.

The University is accredited by the North Central Association of Colleges and Schools.

<sup>&</sup>lt;sup>326</sup> American Indian Relief Council: Living Conditions, http://www.airc.org/living/housing.html, accessed February 24, 2003 .

Reservation are challenging and closely mirror those on the Rosebud Reservation. Per capita income is lowest among all the South Dakota Tribes, averaging \$5,213 in 2000, and over 55 percent of all families on the Reservation have incomes below the Federal Poverty Level. The Bureau of Indian Affairs estimates that unemployment is as high as 80 percent. There are two primary contributing factors to the high unemployment rate: 1) there is no industry on the Reservation, and 2) Non-Indian entrepreneurs own and staff most retail outlets on the Reservation. Access to adequate and affordable housing is also very limited.

Crow Creek Reservation does have its own outpatient health center and dental clinic. Two physicians staff a new Health Center at Fort Thompson (located on the Reservation). Emergency patients are seen after hours and on weekends at Mid-Dakota Hospital in Chamberlain, South Dakota (approximately 20 miles away). When the level of care dictates inpatient services, such services are contracted to area hospitals, the closest being Mid-Dakota.

# Description of Native Women's Health Center (NWHC), Rapid City, SD

The NWHC clinic opened its doors in December 1998 and provides obstetrical/gynecological services to Indian women in Rapid City. The clinic has a staff of 10 and sees approximately 20 patients per day. The clinic is managed and operated by the Oglala Sioux Tribe (Pine Ridge Reservation), under a 638 contract with the IHS, and works closely with the Sioux San Hospital. NWHC offers culturally appropriate pre-natal and post-natal services as an alternative for AI/AN women who would otherwise need to obtain services at a non-AI/AN facility.

## **Description of Other Organizations Interviewed**

Sioux San Indian Health Service Hospital, providing services to AI/ANs residing in or near Rapid City, is the only IHS hospital not located on a Reservation. Sioux San is a 32-bed facility with a staff of ten physicians who provide inpatient and outpatient adult, pediatric, and prenatal care. Major surgery and obstetrics, including complicated cases referred from other service units, are referred to Rapid City Regional Hospital. Inpatient psychiatric care (10 beds), psychological testing, outpatient psychiatric counseling and evaluations are also provided at Sioux San

#### FINDINGS: THE ROSEBUD SIOUX RESERVATION

#### Overview

The Rosebud Sioux Reservation was the first site visit conducted by the project teams. Most site visits required a lengthy process of several weeks to two months to schedule the site visit and to arrange a detailed agenda. President William Kindle of the Rosebud Sioux responded within a few days of receiving the initial project introduction letter, confirmed that they would participate, and assigned a Tribal coordinator to work with the project team to arrange the site visit. The Tribal coordinator, Bill Sorace, worked with the project team to schedule the site visit and arrange for meetings with a wide range of individuals (including County enrollment workers and staff from a non-IHS health clinic near the Reservation) who were knowledgeable and interested in issues of AI/AN enrollment in Medicaid, SCHIP, and Medicare. President Kindle's

interest and prompt response, the level of interest in the community, and the dedicated assistance of Mr. Sorace made it possible to arrange and conduct the Rosebud Reservation site visit within about two weeks of our initial contact with the Tribe.

The site visit included a three hour group meeting in the morning that included the Tribal Health Director and staff, the Director of Community Health Representatives, ambulance services staff, Director of the Tribal Business Office, South Dakota Department of Social Services staff, representatives from the non-IHS Horizon Health Clinic in Mission, SD that serves many Indian people, and a representative from Casey Family Programs. The group meeting was very energetic and informative, covering a wide range of issues and barriers to enrollment and suggesting a variety of approaches to reduce barriers and increase enrollment. An unanticipated outcome of the group meeting was that the Tribal representatives and the DSS staff identified a number of issues of which they had not previously been aware and arranged a follow-up meeting to discuss solutions.

Following the group meeting, the project team met with President Kindle. He was very interested in the issues being addressed by the project and offered his insights and suggestions for addressing barriers to program enrollment. He also expressed great interest in receiving a report on the findings of the case studies and the estimates of eligibility and enrollment that will be produced.

The Director of the IHS facility on the Reservation was scheduled to meet with the site visit team as the final session of the day. Unfortunately, when we arrived at the Service Unit, the site team learned that she had been called away. We therefore met with the Deputy Service Unit Director who had been asked to substitute for the Director. The Deputy Director expressed the view that the most effective strategy for increasing AI/AN enrollment in Medicaid, SCHIP, and Medicare was to refuse to provide Contract Health Services to anyone who had not applied for these programs. In this Service Unit, approval for Contract Health Services is withheld until the patient brings in evidence of application for Medicaid/SCHIP.<sup>327</sup>

Overall, the general consensus of those who were interviewed was that enrollment in Medicaid, SCHIP, and Medicare was substantially low on Rosebud, relative to the number of people who were believed to be eligible. Under-enrollment was stated to be due to both barriers to initial enrollment and to the re-enrollment verification process. Barriers identified and discussed by meeting participants included a spectrum of categories including philosophic, systemic, operational (i.e., policy), and socioeconomic. Interviewees did not think that any single barrier was a major obstacle. Instead, the effect of multiple barriers that were present resulted in a complex and interrelated effect that made it difficult to enroll and maintain enrollment on an ongoing basis.

<sup>&</sup>lt;sup>327</sup> We subsequently learned in other site visits that this is a prevalent requirement for Contract Health Services in most IHS direct service facilities.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Interviewees indicated that barriers to enrollment in Medicaid and SCHIP were the major issue to be addressed on the Rosebud Reservation. There was particular interest in this issue because the Reservation CHRs had recently participated in a CMS/IHS joint project to receive two days training on enrollment processes and eligibility verification leading to State certification of CHRs to conduct enrollment and verify eligibility. However, at the time of the site visit, the CHRs who participated had not yet received certification from the State. There were also a number of concerns expressed about the CHR training program, including: 1) a two-day training period being inadequate to learn the complex details of Medicaid/SCHIP eligibility and enrollment; 2) State confidentiality requirements that restrict CHRs access to the State eligibility data bases; and 3) the perception that use of CHRs to conduct enrollment and verify eligibility could be perceived as shifting the State's programmatic responsibility for these functions to the Tribe, absent any financial compensation.

It was estimated that 20-25 percent of Rosebud Sioux Tribe members were enrolled in Medicaid/SCHIP. However, the low income levels and high unemployment on the Reservation would suggest that significantly more people are eligible than are enrolled in these programs.

#### Barriers to Initial Enrollment

Interviewees most frequently reported the following barriers to initial enrollment in Medicaid/SCHIP:

- There are mixed feelings about the long-term effects of increasing enrollment in Medicaid and SCHIP, because of the potential for diminishing Federal Trust Responsibility. The Aberdeen Area, and particularly the Sioux Tribes in South Dakota, has a strong political and philosophical commitment to maintaining the Federal obligations that were specified in treaties.
- Indian people are reluctant to divulge personal information to strangers (i.e. caseworkers) and, since they are able to obtain services from IHS, do not see a strong reason to reveal personal information to apply for Medicaid/SCHIP. In addition, some people who live in multiple family households are concerned that, if they provide information on their living arrangements, the caseworkers and/or other State or County officials may use that information to reduce benefits for other household members.
- Many people do not know that they are eligible for enrollment in Medicaid or SCHIP. There also is considerable misinformation (e.g. if you get Medicaid, then the State will take your house when you die).
- Many Indian families do not understand that they would not be liable for co-payments as long as they obtain services through the IHS.
- Many people see no advantage to enrollment in Medicaid and SCHIP. However, the Indian Health Service is under-funded and local IHS staff recognizes that revenues from other sources would improve timeliness and access to services both for the Medicaid/SCHIP enrollee and for everyone in the community.

- Some people on the Rosebud Reservation have limited literacy skills and find it difficult to understand complex directions and information even when it is provided. Some do not have telephones; some do not have a specific address for mail; and other communications that are important to the enrollment process.
- The enrollment process is complicated; many people find it difficult to understand and complete the enrollment forms and may not have the necessary supporting documentation.
- Caseworkers and social workers have large caseloads and do not have adequate time to help everyone who needs help in completing paperwork. The pilot CHR program, implemented jointly by CMS-IHS, was meant to add additional resources to help with the application process, but was not perceived to have been successful.
- The enrollment process requires at least one, and sometimes multiple trips to the County offices to complete the application. However, many people live far from the closest local County office and have limited access to transportation. As a result, even when people begin the application process, they may never complete it. (While South Dakota SCHIP does permit mail-in applications, most AI/ANs are used to and prefer face-to-face assistance).

#### Barriers to Maintaining Enrollment

Even when people become enrolled in Medicaid or SCHIP, the requirement for both annual and periodic redetermination of eligibility results in loss of coverage for some people. All enrollees in both the Food Stamp and Medical Assistance programs are subject to an annual redetermination requirement, which is conducted at the beginning of each year. Redetermination requires current enrollees, and applicants alike, to report their income, expenses (e.g., day care and child support), as well as how many people live in their household. In addition to the annual redetermination, enrollees are expected to report specified economic/housing "changes" to their local DSS office, e.g., if someone has a new job or if people have moved in/and or out of a household.

South Dakota does require monthly *reporting* (not to be confused with redetermination) for enrollees in the food stamp program; however, if someone should fail to report as required, they could be temporarily disenrolled awaiting redetermination. While the DSS caseworkers do make some effort to contact people who are undergoing redetermination and offer assistance, the caseworkers' workload is so great that only limited time can be devoted to this process. The State does permit a two-month grace period for re-verification – that is, people are not terminated from the program unless they have not provided the re-verification information within two months of the original due date.

The primary barriers to completing the re-verification process successfully, include:

• The requirements for redetermination are burdensome and offer the potential to have the materials lost in the mail, overlooked by the recipient, not received by the recipient, or other misadventures in reporting.

- Most enrollees receive redetermination requests by mail and some find the requirements difficult to understand and meet. Although caseworkers may be available to assist in completing the paperwork, obtaining this assistance requires travel to County offices, possibly several times.
- Tribal health departments, CHRs, and others could assist people to complete redetermination paperwork, but due to State privacy requirements the information on individuals who are due for redetermination can not be provided directly to the Tribe.

# <u>Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings</u> Programs<sup>328</sup>

For elderly Rosebud Sioux, enrollment in Medicare Part A was not perceived to be an issue. People who had worked for 40 quarters are automatically enrolled and most who are enrolled are aware of their coverage. Interviewees, however, said that many elderly Medicare beneficiaries were not enrolled in Part B. Interviewees also believed that there was significant under-enrollment in Medicare of those who are physically disabled and would be eligible if they were able to qualify for Social Security Disability Income coverage.

Barriers to enrollment in Medicare and in the Medicare Savings Programs that were identified by interviewees included:

- The Medicare Part B premium is high relative to incomes and many beneficiaries are unwilling to pay the premium since they can obtain most Part B services through the Indian Health Service.
- The process of applying for Social Security Disability Income eligibility is very complicated and lengthy and few people are persistent enough to complete the application process. In addition, the SSA is perceived by many AI/ANs as always turning people down the first time they apply and the interviewees felt that most Indian people do not continue to pursue seeking SSDI after the first rejection.
- Most AI/AN people are not aware of the Medicare Savings Programs and do not apply for QMB/SLMB coverage. If they are aware, or are made aware by IHS or by DSS caseworkers, the same barriers that exist for general Medicaid enrollment deter people.

## Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

A broad range of suggestions was offered by those interviewed. For instance, IHS staff screens patients for eligibility for programs and provide some assistance in helping people enroll. The primary approach, however, is the "stick approach" of refusing to approve Contract Health

<sup>&</sup>lt;sup>328</sup> The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

Services for those who have not applied for public program coverage. Interviewees said that there were a number of specific and broader strategies that could be implemented that would encourage and facilitate enrollment in public insurance programs, including:

- **Develop and implement educational programs** on the Reservation to 1) help people to understand that enrolling in Medicaid, SCHIP, and Medicare provides better access for enrollees to both Indian Health Service services and to Contract Health Services; 2) educate people about the lack of funds for IHS services and Contract Health Services and how their enrollment in public programs increases revenues and services available for all Indian people on the Reservation; and 3) dispel myths about the programs (e.g. enrolling in Medicaid does not mean that the State will confiscate properties, and co-payments are not required for Indian beneficiaries who obtain services through Medicaid or Medicare).
- Increase funding for enrollment assistance, both for the State and for the Tribe. There is a need for more caseworkers (or other paid or volunteer staff), in general, and specifically to provide one-on-one enrollment assistance (in the client's home to facilitate enrollment, if necessary). The CMS-IHS project to train CHRs on eligibility and enrollment assistance was judged a good idea, but to be effective would require more extensive training and also would require cooperation from the State to ensure that CHRs could be certified and have access to the State's eligibility data.
- The State of South Dakota should review all income guidelines and simplify as much as possible. The State has approximately 15-20 different sets of income guidelines for various social service programs. This seems to add an unnecessary level of complexity to an already confusing system. As a result, applicants often have to pick and choose which program (i.e., benefit package) for which to apply. By reviewing all income guidelines, and collapsing them when appropriate, this effort might actually reduce the State's workload—thus saving money and reducing the complexity of the application process.
- An annual meeting among State, County, Tribal communities, and IHS staff to discuss/strategize about barriers, issues, and enrollment protocols would encourage better working relationships and help to identify and develop joint solutions to problems.
- Eliminate the mail-in Medicaid application process. Clients do not understand this process and are unable to complete the form without assistance. Although it is intended to address transportation and privacy issues, it is seldom successful and deters people from applying.
- **Tribal involvement in developing State Medicaid eligibility.** The Tribe would like to be more involved in developing State Medicaid eligibility, application, redetermination, and reimbursement regulations.

#### FINDINGS: CROW CREEK RESERVATION

#### Overview

Federal government, South Dakota State government, and Tribal government relationships were a strong concern at Crow Creek. The Tribe has very few financial resources

and has the lowest per capita income of any Tribe in South Dakota. A local news report (August 19, 2002) reported that the Tribe was \$31 million in debt and, as a result, some Tribal members had petitioned the Federal government, through the Bureau of Indian Affairs, to take over management of the Crow Creek Sioux Tribe.<sup>329</sup>

Wanda Well, Tribal Planner, conducted coordination and scheduling of the site visit. Meetings were held with the Tribal Chairman, Tribal planning staff, the director of the Crow Creek Head Start Program, Tribal health department staff, the CEO of the Fort Thompson Indian Health Service Health Care Center, and other staff from the IHS facility. In addition, the project team met with elders at the Tribal Golden Age Center, and with other interested Tribal members at a one-hour open meeting at the end of the day. Project team members also had met with the DSS District Supervisor for Crow Creek, during the previous day in Pierre, to obtain her views and input on barriers to enrollment of AI/AN people into Medicaid and SCHIP.

The Tribal Chairman began our meeting by stating that theirs is the poorest Reservation County in the nation. He stated that the State should do more to alter/remove this "disgraceful statistic." With that said, he added that he viewed this project and our site visit as an opportunity to make the Tribe's case for assistance on many levels.

With respect to the Medicare and Medicaid programs, the Tribal Chairman said that Tribal members generally feel a "great wariness against the white world." He also noted, however, that "My people aren't sitting around in teepees anymore and they need to get over it." He also stated that, although the application process for Medicaid is "intimidating, the end result is worth the time and effort." Still, he believes that AI/AN people, in general, only think about enrolling in such programs when they are in need of medical services.

The Chairman also stated that State-Tribal government frictions were a problem that would need to be resolved before enrollment in Medicaid/SCHIP would increase. "Anytime there is interaction between the Tribe and the State, there is conflict... and even subtle racism." As a result, "Indian people will often pull back when approached about enrolling in programs." State Agency officials and staff were accused of believing that the money spent on reimbursing health care services on the Reservation is THEIR money, when, in fact, Medicaid services to AI/AN people are paid with Federal, not State dollars. When seeking information from the State DSS, AI/ANs are advised to phrase their questions carefully, since the attitude among some DSS workers seems to be, "If you ask me the <u>right</u> question, I'll tell you – if not, I won't."

The Tribal Chairman expressed his opinion that, by delegating Medicaid and SCHIP administration to the States, that the Federal government has made a national policy decision that Tribes are to be "dealt with" through the States. He said that the Office of Tribal Affairs in Pierre was a good concept, but the State has "a ways to go before native people are treated equally." To make the point, he also noted that there are very few AI/ANs working in the DSS and suggested that perhaps there is a stigma against working there, or perhaps, it may be due to subtle racism.

<sup>&</sup>lt;sup>329</sup> Black Hills Pioneer, August 19, 2002, p. 22.

# Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

There was consensus among the interviewees that there is an under-enrollment problem for residents of the Reservation.

#### Barriers to Initial Enrollment

Some of the primary factors that were identified by interviewees included:

- DSS officials and Tribal members concurred that one reason for low enrollment is that AI/ANs have been promised health care services by the Federal government and, therefore, the Federal government has a responsibility to provide these services.
- Some interviewees said that local DSS staff has a reputation of being rude to AI/AN people and applicants are "frightened" when they see caseworkers. "DSS needs to do a better job of providing services on the Rez." The State's public assistance (TANF) intake process is also humiliating, "People don't want to participate, even though this is a way to get health coverage." Conversely, other interviewees described County caseworkers as "very dependable." Then again, "DSS workers make you feel so bad about yourself." Several interviewees strongly believed that the rudeness and difficulties encountered were the result of specific attitudes toward AI/AN people. Elders who were interviewed did not sense any racism in their encounters with caseworkers; they suggested this might be an issue specifically with younger residents of the Reservation.
- Enrollment is facilitated by face-to-face assistance, but this is not available. At one point, TANF/Medicaid outreach worker workers were stationed on the Reservation, but this arrangement was discontinued some years ago.
- The complexity of the application process and low levels of literacy of some eligible people is a serious barrier to enrollment. Even though the Medicaid application has been simplified, many people still have difficulty understanding and completing the forms successfully.
- Travel distances and lack of transportation makes it difficult for people on the Reservation to obtain assistance in completing the application forms and process. If there is difficulty in finding a ride and frequently there is and a scheduled appointment is missed, they are "turned away at the door" and have to schedule a new appointment, often 30 days later.
- The Tribal Health Department is responsible for ambulance services and some diabetes education and programs, but is not able to meet State requirements to become a State certified provider. Because Tribal health departments (and programs) cannot meet State standards, they cannot receive reimbursement for Medicaid covered services; therefore, program staff has limited incentive to promote/enroll patients.
- The State does little to market the availability of Medicaid and SCHIP enrollment and eligibility standards specifically on the Reservation. Tribal staff frequently see bulletins outlining new restrictions to the delivery and/or reimbursement of health care services –

"never do you see one that urges those eligible for Medicare/Medicaid to sign up for the programs."

- There is distrust of the intent of caseworkers to maintain confidentiality of information that must be provided on the application forms. There is a belief that caseworkers often breach confidentiality and talk openly about applicants.
- There is a perception on the Reservation that the State and caseworkers are biased against AI/AN people and actively discourage AI/ANs from enrolling. Some interviewees believe that State agency staff sees Medicaid eligibility as a "freebie to the Indian people"; "These aren't State dollars, they are Federal... and Indians need to feel it's Federal."
- There is inadequate effort by the State, the IHS, and Tribal managers to educate and inform AI/AN people about the benefits that enrollment in Medicaid/SCHIP/Medicaid provide the Reservation and Tribe.
- The application process requires that income and other information about all household members be reported, even for unrelated people living in multiple family households. Applicants may be reluctant to apply for fear that the information could be used to take away benefits already received by some household members. As well, there is a perception that this requirement may result in denial of eligibility for Medicaid and SCHIP, based on inappropriate assignment of income of household members to the person who is applying. "The State is using pregnant girls' parents' income as a way to deny their application." The applicant needs to have a physical address to apply for social services, and the form requires that everyone living at that address be identified, including his/her income.
- There is concern among some people that enrollment in SCHIP places a child at risk of being taken away by the State. Many grandparents (who are often the guardian of a minor) do not enroll a child because they "don't want to be part of the system."

## Barriers to Maintaining Enrollment

Interviewees did not cite any barriers to maintaining enrollment in Medicaid and SCHIP.

#### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Interviewees stated that under-enrollment in Medicare is a problem, particularly for Part B. Reasons include:

• Many Tribal elders cannot pay the Medicare Part B premium. After paying life insurance premiums from her Social Security check, one elder said she has only \$30 left for the entire month, and that is not enough to even consider enrolling in Medicare Part B.

- Elders lack information on where to go and who to see for face-face information about Medicare. For example, there are no elder-specific orientation programs on the Reservation to familiarize an elder with the benefits of Medicare. Exacerbating this problem is that illiteracy or limited English language skills among many elders limit understanding of the benefits of Medicare.
- There is little information or source of assistance for disabled people who may qualify for Social Security Disability, and subsequently for Medicare. The process of applying is too complicated, lengthy, and is perceived to seldom lead to approval and benefits.

#### Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

Several interviewees cited one current strategy, in place on the Reservation, as a successful way to increase Medicaid and SCHIP enrollment. After repeated requests, the State finally put a DSS mailbox on the Reservation (as a drop-off point for DSS reapplication/application forms). That simple act has saved many from having to make a trip to the local DSS office when transportation is not always available or reliable. However, the salient point was that it took "years of complaining" to finally enact this change. Other strategies that were suggested included:

- Educational materials about the benefits and applications process for the Medicare Savings Programs. The State DSS could provide more educational materials about the benefits and applications process for QMB/SLMB to more individuals on the Reservation; one group of about nine elders interviewed never heard of these programs. In addition, a request was made for a brief, easy to read and understand article about EPSDT.
- Workshops on cultural competency/sensitivity for all DSS staff. DSS should conduct
  more workshops on cultural competency/sensitivity for all DSS staff. As an example of
  the practical application and affect of such training, DSS staff would broaden (hopefully)
  their perspective as they assess what is truly in the best interest of Indian children under
  the State's care.
- Training of Community Health Representatives (CHRs). CHRs could prove helpful with education/enrollment, but they would require adequate eligibility/enrollment training. Through their increased involvement, they might be able to generate enough additional revenues for the health care system to pay for their training and additional duties. However, there seems to be some degree of confusion as to where the responsibility for program enrollment lies; there is suspicion that the State may regard CHRs as an inexpensive "replacement" for additional caseworkers and that this strategy might permit the State to "shirk its responsibility."

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<sup>&</sup>lt;sup>330</sup> South Dakota does have a State Health Insurance Assistance Program (SHIP) with an 800 telephone number to assist elders with Medicare issues, but there was no awareness of this source of assistance among the elders who met with the project team at Crow Creek.

- **Tribal DSS staff position**. The State could fund a Tribal DSS staff position so Tribal members do not feel so intimidated when calling the State for appeals, assistance, and information.
- **Home visits to help with Medicaid and SCHIP applications.** Head Start is doing home visits and sometimes helps with Medicaid and SCHIP applications. This role could be encouraged and expanded.
- **DSS office waiting rooms**. If possible, local DSS office waiting rooms should be provided with toys to occupy children who accompany parents who are applying for coverage.
- **Formal, regularly scheduled meetings** between Tribal leaders/health staff and State DSS officials would be beneficial to address and resolve issues and to communicate information about Medicaid and SCHIP changes.
- **Head Start.** The Head-Start program has been successful on the Reservation because of the amount and frequency of education about this program. To replicate this level of success, it was suggested that the local IHS facility, in collaboration with the State, develop a similar educational campaign to provide Tribal members information about Medicaid, SCHIP, and Medicare Savings Programs.
- The State should allow eligibility determinations to be made locally. Interviewees stated, "This option will never happen in this State."

## FINDINGS: RAPID CITY URBAN INDIAN HEALTH FACILITIES

## **Overview**

About 15 percent of the approximately 60,000 total population of Rapid City, South Dakota is AI/AN. Rapid City is located in the western half of the State, about 60 miles from the Wyoming border, and is the second largest city in the State. Three large Reservations – Pine Ridge, Rosebud, and Cheyenne River – are all located within a 100-mile radius of Rapid City. There is considerable migration, in both directions, between the Reservations and Rapid City. The reasons for the outbound migration is that AI/AN people are seeking jobs and other services not available on the Reservations. The reasons for the inbound migration are varied: AI/ANs could be returning to the Reservation after a period of seasonal work, visiting family for extended periods of time, or seeking cultural commonalities not found in the urban areas.

The project team visited two health facilities in Rapid City. Sioux San Indian Health Service Hospital is the only IHS facility in the nation that is located in an urban area. The Native Women's Health Center (NWHC) provides obstetrical/gynecological services to AI/AN women and is managed by the Oglala Sioux Tribe (Pine Ridge Reservation) under a P.L. 93-638 contract with IHS. Physicians from the NWHC have admitting privileges at Sioux San Hospital and oversee deliveries at the hospital. The project team met with the Chief Executive Officer (CEO) at Sioux San and with the Business Office manager and staff, with the Benefits Coordinator, and with the Pine Ridge health system administrator who works closely with Sioux San staff to

coordinate services between Rapid City and the Reservation. At the NWHC, meetings were held with the Front Office Administrator, medical staff, and business office staff.

Interviewees said that raising the issue of enrollment in Medicaid and SCHIP to patients, as part of their professional duties, presents them with an "ethical quandary." While their facilities desperately need the revenues from Medicaid and SCHIP, these interviewees said that applying for Medicaid and SCHIP can be a "humiliating experience" for people. One of the main reasons given by their patients for not enrolling is that, "Treaty rights guarantee medical services."

In addition, the Sioux San CEO said that enrollment of Sioux San patients is a double-edged sword. Sioux San is under-funded and needs the additional third-party revenues to provide services and access. However, when a patient enrolled in Medicaid, SCHIP, or Medicare must be referred for specialty care to Rapid City Regional Hospital,<sup>331</sup> it is not uncommon, once the condition has been stabilized, for that patient to never be referred back to Sioux San. Sioux San's CEO has met with the management at Regional to address this issue; yet nothing seems to get resolved.

## Current Enrollment and Barriers to Enrollment in Medicaid /SCHIP

Interviewees at both urban facilities agreed that under-enrollment in Medicaid and SCHIP is a problem for their patients.

#### Barriers to Initial Enrollment

Some of the barriers to enrollment they identified include:

- The private medical community is not particularly concerned about a patient's enrollment status until a bill is not paid. Private practitioners' active involvement in enrollment efforts could be beneficial in identifying eligible clients.
- The number of Medicaid participating physicians is inadequate to meet the need for services. When Medicaid beneficiaries see private physicians, they are then billed for the balance of the doctors' bills that Medicaid does not cover. This practice imposes, at times, an impossible financial burden on the recipients of the bills. The lack of Medicaid participating physicians is well known and causes some eligible people not to enroll because they believe services will not be available, or that they may incur out-of-pocket costs that they cannot afford.
- Intake processes among clinics and IHS facilities lack consistency. One clinic does inquire about enrollment status during intake, but if the response is, "no," the questioning stops; no additional Medicaid enrollment or informational efforts are initiated. The patient's attitude is also an effective deterrent to a more aggressive approach at intake:

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<sup>&</sup>lt;sup>331</sup> Rapid City Regional Hospital is a private not-for-profit facility and provides contract services to Sioux San Hospital. Rapid City Regional Health System controls the majority of health services within the Western South Dakota area and is the dominant health care system.

- "Here we are, we need services...and the clinic cannot turn any us away. Besides, we don't see the IHS hospital requiring enrollment of everyone who is eligible in Medicaid."
- The complexities and rules governing the State's social services programs are very confusing to the client; even agency staff is challenged to keep eligibility requirements straight.
- Some interviewees thought that some, though not all, caseworkers themselves posed a barrier to enrollment; some reportedly "degrade Indians" who are enrolled on Medicaid, while others seem quite sympathetic. An example was given of one caseworker that did not inform a client (who left TANF) that her children were eligible to enroll in SCHIP. There also was a concern that caseworkers deliberately do not inform AI/AN clients that they can choose Sioux San Hospital as their PCP.
- Caseworkers are not always customer responsive, e.g., the window for new applications is only open between 8 a.m. and 9a.m.; a limitation that is "totally unrealistic." If someone needs to apply for Medicaid, SCHIP, and TANF, the applicant needs to go to two different buildings, which requires transportation that is not always available. The caseworker has the ability to make this process easier, or even more difficult.
- Some applicants will stop completing a Medicaid application when they see the question that requests naming the father of a child. The State requires this information so they can pursue child support and some social workers will often pressure the applicant to provide such information. Some reluctance in providing a name stems from the belief that if the father is currently incarcerated, he will face a child support "fine" upon their release from prison.
- Under State rules, an individual with a diagnosis of alcoholism, even if it is the fourth or fifth diagnosis listed, "should be denied enrollment" in Medicaid. At one time, the applicant could be enrolled with a diagnosis of substance abuse but this policy seems to have changed and the State cannot seem to differentiate between substance abuse and alcoholism.

# Barriers to Maintaining Enrollment

• TANF requires monthly verification of income. If there is a \$25/month change in income an applicant can be "knocked off" TANF for that one day. And, removal from TANF results in a denial of access to Medicaid – "It is a humiliating experience" – when seeking medical services, the receptionist swipes their Medicaid card through a terminal and gets a "no services" response.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

• Income from Tribal trust lands is included in the LTC formula and this creates and reinforces fears of eState recovery for those enrolled in the Medicare Savings Programs.

• Interviewees stated that "everyone" (both applicants and those who assist them with their application) expects that the first application for SSDI will get denied. For those cases that ultimately do receive approval, the process still takes 3-4 years, during which time the individual does not receive Medicare benefits. Some Indian people give up when they receive the denial of the initial application. Exacerbation of this problem occurs if the benefits counselor is not aware of the denial and is not able to assist with the reapplication.

# Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

IHS staff had multiple suggestions and strategies to increase enrollment. They include:

- Additional outreach and application assistance is needed. One strategy is to involve non-profit organizations that have resources to provide assistance to the application process. The Native American Heritage Association (NAHA), a nonprofit organization in Rapid City helps the Native Women's Health Clinic by providing travel funds and transportation to prospective patients who may be eligible for enrollment.
- Improved communication and understanding between the State and AI/AN Tribes and health providers. Interviewees recommended that a process be established to improve communication and understanding between the State and AI/AN Tribes and health providers. It was suggested that an annual meeting be held in Rapid City with State, IHS, and Tribal leaders and health directors, to address areas of conflict, identify where interaction between AI/AN Tribes and providers and the State is effective, and jointly develop solutions.
- The State should provide access to Medicaid and SCHIP enrollment and anniversary date data to the Tribes and IHS facilities. If an IHS facility had Medicaid and SCHIP enrollment and anniversary dates, they could easily flag medical files and notify patients when they need to re-apply. In addition, there is no cross-reference data source where Tribal CHRs can confirm eligibility/enrollment in Medicaid and SCHIP so that they can provide outreach and assistance. 332
- **Elimination of child support information.** The State should eliminate the child support form from the Medicaid and SCHIP application process.
- **Simplification of income eligibility standards.** The State should simplify the income eligibility standards across programs to help people apply for multiple program enrollments on one form.
- **Prohibit program denial based on alcoholism.** The State should change the rule that says, if alcoholism is diagnosed even if it is fourth or fifth on the list the applicant should be denied enrollment.

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<sup>&</sup>lt;sup>332</sup> The State responds that it is unable to provide access to enrollment and anniversary date data because of privacy and confidentiality requirements.

- Improved working conditions and salaries of caseworkers. Improving working conditions and salaries of caseworkers would provide more stability and encourage retention of knowledgeable, experienced caseworkers. Social workers have a high attrition rate in many areas of the State due to a combination of high stress and low pay. In fact, interviewees said that most State employees qualify for food stamps if they have a family.
- Modification of monthly income verification requirement. The State should consider modifying the monthly income verification requirement. When someone on Medicaid has a \$25 dollar increase in income on any given month (or day for that matter), that individual no longer qualifies for benefits that month or day.
- Medicaid and SCHIP AI/AN liaison on each Reservation and in IHS facilities. The State should consider hiring and establishing a Medicaid and SCHIP AI/AN liaison on each Reservation and in IHS facilities. This staffing change would, at the least, save on phone bills by reducing the number of calls to the State DSS office in Pierre. AI/ANs who are eligible for enrollment would be more likely to complete the process if they have a culturally-sensitive person to work with on a face-to-face basis, and if they are not required to travel to County offices.
- Organization and tracking processes to identify and assist with enrollment. Within IHS and Tribal health facilities, organization and tracking processes to identify and assist with enrollment could be more effective. Patient registration used to be a part of Medical Records but has been reorganized into the IHS Business Office, so that every patient record gets updated for Medicare, Medicaid, or SCHIP eligibility at intake. To verify that a Medicaid-eligible patient did not slip through the intake process, the benefits coordinator could attend "morning rounds" along with the physician. Such an oversight could typically happen in one of two ways: 1) if the hospital does not use a social security number to ID their patients, and 2) if the patient came through the ER. Another strategy is to put in place a process to ensure that, at the registration desk, each patient is asked specifically about enrollment status in Medicaid, Medicare, or SCHIP so that every patient record gets updated at intake. If the patient is not enrolled, and does not have private insurance, they should be referred to a benefits coordinator (if such a detour does not interfere with the patient's appointment).
- Improving internal data systems in health facilities. Within IHS and Tribal health facilities, improving the accuracy and making effective use of internal data systems could also be a strategy for increasing enrollment. The IHS Resource Patient Management System (RPMS), a database system, and Patient Care Component Plus (PCC+), a customizeable encounter form, are used to maintain inpatient records. The PCC+ generates a report that indicates whether a patient is covered by Medicare, Medicaid, SCHIP, or other insurance.
- Establish Tribal Medicaid and SCHIP programs. The Federal government should consider establishing Tribal Medicaid and Tribal SCHIP, similar to the Tribal TANF program. This would encourage Tribes to take on greater responsibility for outreach and enrollment, and would likely reduce barriers to enrollment that are related to fears of

interaction with the State government agencies. Additionally, by eliminating a middle layer, the State would also save time and money. Tribes should be empowered and the State regulations and standards that control access to Federal programs should be eliminated.

- Shift responsibility for determining eligibility for Federal programs to the IHS or Tribally managed health facility. This particularly makes sense for Medicaid, since the Federal Medicaid Assistance Percentage (FMAP) is 100 percent for AI/AN beneficiaries receiving services in these facilities and no State funding is provided.
- Disseminate information about Federal Poverty Level changes each year, along with new forms, applications, and materials to clinics, schools, Head Start, etc. This information would encourage people to consider whether they are eligible and, perhaps, prompt them to apply.
- Ask specifically about enrollment status in Medicaid, Medicare, or SCHIP at the health facility registration desks so that every patient record gets updated at intake. If the patient is not enrolled, and does not have private insurance, they should be referred to a benefits coordinator (if such a detour does not interfere with the patient's appointment).
- Train Community Health Representatives (CHRs). CHRs should be trained to do enrollment; however, the maintenance of continuing eligibility is costly/complex so funds should be provided for enrollment services only.
- **Provide enrollment information and application assistance at schools.** When parents attend parent-teacher conferences, a table should be staffed and available to provide enrollment information and personalized application assistance.
- Encourage State caseworkers to refer AI/ANs to IHS or Tribal health facilities. The State's caseworkers should refer, or at least recommend, Sioux San Hospital to AI/AN applicants (which is not done consistently) because Sioux San Hospital can then obtain 100 percent reimbursement from CMS. Referrals to other providers result in added costs to the State.

## Other Issues

A number of other issues were raised by IHS staff, some of which were indirectly related to barriers to enrollment and/or strategies that would create incentives for increased enrollment efforts. For example, interviewees cited some degree of caseworker mismanagement by State agencies interested more in compliance with CMS/State standards and multi-program operating requirements, than with facilitating "access" to health care. Interviewees also identified a failure to conduct outreach that is "welcoming" rather than "demeaning" to program applicants.

# FINDINGS: SOUTH DAKOTA MEDICAID AGENCY AND OTHER STATEWIDE ORGANIZATIONS

# South Dakota Department of Social Services and South Dakota Urban Indian Health, Inc.

#### Overview

In addition to interviews on the Rosebud Reservation, Crow Creek Reservation, and at Urban Indian Health facilities in Rapid City, the project team also met with State government officials in Pierre and interviewed the Executive Director of South Dakota Urban Indian Health, Inc. (the association of urban Indian health facilities in South Dakota).

# **South Dakota Department of Social Services**

The project team met with representatives from the Office of Economic Assistance, Department of Social Services. The Office of Economic Assistance (OEA) is responsible for TANF, Food Stamps, and Medicaid and SCHIP eligibility and enrollment. Participants in that meeting included the Administrator for Economic Assistance and the Assistant Program Administrator, TANF and Medicaid. A meeting was also held with the Commissioner, Tribal Government Relations. At the time of the meeting, the Office of Tribal Government Relations was an independent office and the Commissioner reported directly to the Governor.<sup>333</sup>

The meeting with DSS began with introductions and the project team provided an overview of the purpose of our visit. The DSS/OEA managers noted that related studies had been funded in the past by CMS. The managers emphasized the need for improved communication among the various Federal agencies regarding efforts to improve access. The Administrator of the OEA asked whether increasing enrollment in State Medicaid and SCHIP programs was, in fact, an appropriate strategy, when the primary underlying issue was that the Federal government has chosen to under-fund the Indian Health Service.

The OEA/DSS administrator asserted that, compared to very poor non-Indian people, American Indians appear to be somewhat more sensitized to the need/benefits of enrollment in Medicaid/SCHIP and, therefore, are more likely to enroll. However, the Commissioner of Tribal Government Relations did not completely agree with that assumption and said that he believed that there is under-enrollment of Indian people in these programs.

District DSS supervisors have taken a primary role in increasing Medicaid enrollment. To facilitate enrollment, applications are "pended," for 45 days – but not denied – if information is missing from the application. If the necessary information has not been received after 45 days, the application is then denied. In many instances, the State is able to obtain missing information from alternate sources, and thereby, "not bother the applicant at all." This includes calling employers to request income verification (a signature on the application allows the State to do this).

<sup>&</sup>lt;sup>333</sup> A new Governor, Mike Rounds, took office in January 2003. He plans to re-organize the Office of Tribal Government Relations and place it within the State Development Department.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

The OEA staff also said that Tribal governments do not do an effective job of informing and educating Tribal members about the benefits to the Tribe of enrollment in Medicaid and other public programs. As a result, American Indians do not appreciate the value of public programs for themselves and for their Tribes.

#### Barriers to Initial Enrollment

Barriers to enrollment that were identified by OEA included:

- DSS officials have heard that one reason for low enrollment is that American Indians have been promised health care services by the Federal government; therefore, they do not have incentives to enroll.
- One primary point of contention between Tribes and the State is relocating children on the Reservation who are under the custody of DSS due to negligence. Once DSS takes a child under its wing, "regulatory barriers get in the way" of the extended families wishes and abilities. Indian people traditionally rely heavily on extended families for rearing children in addition to the "legal" guardian. This cultural practice runs counter to DSS policies, although DSS does try to work with a grandparent, if they are "stable." It is scenarios like this that help push potential enrollees away from State-sponsored programs.
- To the family, enrollment is a health care issue, but to the IHS enrollment is a funding issue two perspectives that require different, and not necessarily compatible, solutions.
- DSS questioned the appropriateness of a policy that requires IHS to provide services "within their walls" in order to receive payment. Transportation is a huge issue on Reservations, and, in their opinion, CMS has placed a barrier directly in the path for those who need services
- The lack of involvement of the medical community/providers in encouraging and assisting enrollment is a barrier that is difficult to overcome. As a group, providers do not seem particularly concerned about enrollment status, until a bill of theirs is not paid. The active involvement of physicians and their office staff could be quite beneficial in identifying eligible clients.
- Former Governor Janklow's mission to make "dead-beat parents" (all parents, not just Indian parents) pay their fair share is not necessarily unreasonable; however, it may be a barrier to enrollment.

#### Barriers to Maintaining Enrollment

Interviewees did not cite any barriers to maintaining enrollment in Medicaid and SCHIP.

# <u>Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings</u> Programs<sup>334</sup>

The interviewees did not document any barriers to Medicare or the Medicare Savings Programs.

# Strategies to Increase Enrollment in Medicaid and SCHIP

The OEA staff said that there have been a number of efforts to increase enrollment of AI/ANs into Medicaid and SCHIP in South Dakota. One program (funded by an unknown grant source) provided funding for two women from Pine Ridge to go on a door-to-door campaign to assist individuals to enroll in Medicaid. Applications were marked to track their effectiveness. Enrollment statistics were not available the time of our interview, but this effort was believed to be unsuccessful. DSS heard that parents believed they were filling out a form for their children to participate in school athletics.

OEA/DSS staff offered the following recommendations:

- Expansion of the CHRs role to assist in the enrollment process. Interviewees stated "They know enough to help, and most States have simplified the application form and process and CHRs could simply pass them out."
- More education to the AI/AN community by the Department of Social Services about the benefits and process of enrolling.
- More workshops on cultural competency for DSS staff. This would assist DSS staff to assess what is in the best interest of AI/AN children under the State's care.

#### South Dakota Urban Indian Health, Inc.

# <u>Overview</u>

The Executive Director of South Dakota Urban Indian Health, Inc., Donna Keeler, was unable to meet with us while we were in Pierre, but talked with us by telephone subsequently. The South Dakota Urban Indian Health, Inc. represents urban AI/AN health clinics in Pierre, Sioux Falls, and Aberdeen. All three of these facilities are authorized to serve as Primary Care Providers under the State's Medicaid managed care program.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

The Executive Director noted that both in Pierre and in Aberdeen there is only a small number of AI/AN people enrolled in Medicaid because a high proportion are Federal or State

<sup>&</sup>lt;sup>334</sup> The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

employees and have incomes that are well above the Medicaid or SCHIP eligibility levels. In Pierre, patients who appear to be eligible for Medicaid or SCHIP are referred to the local DSS office. Clinic staff will often assist the patient by making an appointment with DSS for them and, if necessary, accompanying them to DSS.

#### **Barriers to Initial Enrollment**

Enrollment in Medicaid or SCHIP requires a lot of paperwork and many people find it confusing and difficult to complete. There is not sufficient assistance available to help them get through the process successfully.

# Barriers to Maintaining Enrollment

Health facilities do not have access to the eligibility rolls through the State and so cannot identify people who are coming up for re-verification of eligibility. As a result, some people lose eligibility that could be assisted if staff knew that they were in the redetermination process.

# Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

The Executive Director said that Medicare is too difficult to deal with and that the urban AI/AN clinics do not bill Medicare. She opined that Medicare has too many rules and is out-of-touch with the realities of the health care world; "It's not worth the trouble." As a result, there is less interest in providing assistance to enroll people in Medicare and in SSDI.

# Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

The Executive Director said that there have been some effective programs developed and implemented in South Dakota. One example is that the State Medicaid program has contracted with Augustana College to conduct outreach on SCHIP and to provide SCHIP outreach and enrollment training to urban Indian health facility staff in Sioux Falls. The training is quite thorough and staff at the Sioux Falls facility help patients fill out and complete the application forms, with the result that most eligible people successfully enroll. Suggestions put forth by the Executive Director for other strategies to increase enrollment included:

- Outstationed State caseworkers. The State DSS should consider out-stationing a caseworker, at least one day a week, at Urban Indian Health facilities to provide face-to-face convenient assistance to people who are eligible and applying for Medicaid/SCHIP.
- "Ticker" file for redetermination cases. The State should find a way to provide information on people who are scheduled for re-verification of eligibility to health facilities so that staff can contact them and offer assistance with the redetermination process.
- Reduce administrative complexity of Medicare. CMS should re-structure the Medicare program to be less administratively complex and burdensome to small providers who do not have staff and resources to meet the current regulatory requirements, but are in a critical needs/rural area and providing services to Medicare beneficiaries.

#### **DISCUSSION**

The State of South Dakota and the AI/AN Tribes within its borders have a long history of difficult government-to-government relationships. There also is perceived – and perhaps actual – racial bias toward AI/AN people by some of the non-AI/AN population of the State. This history combines with geographic isolation, severe poverty and unemployment on Reservations, and health status of AI/AN people that is the worst of all IHS regions in the nation, to affect the willingness and capacity for AI/AN people in this State to apply for enrollment in public health programs.

Generally speaking, the AI/AN interviewees that the project team met with believe that under-enrollment of AI/AN people in Medicaid, SCHIP, and Medicare is a significant problem in South Dakota. In part, South Dakota AI/ANs believe that under-enrollment is the result of the State of South Dakota's institutional bias against AI/ANs who seek assistance from State social and health programs.

In contrast to the AI/AN viewpoint, interviewed State officials do not believe that a significant gap exists between those AI/ANs who are eligible and actually enrolled. However, State agency officials confessed that they "have not spent a great deal of time" thinking about increasing enrollment – their inference was that in South Dakota, there is not an underenrollment problem – but agency staff admitted it is impossible to really know for sure. The State's perspective that all that can be done is being done is based upon: 1) the belief that existing outreach/enrollment efforts are highly effective; 2) one study (conducted for the Robert Wood Johnson Foundation's Covering Kids grant) found that most AI/AN children at Eagle Butte, South Dakota, were enrolled; 3) case-loads for eligibility workers are not excessive or in a "pending" status very long; and 4) the belief that most AI/ANs are unemployed and receive State economic assistance already. Therefore, interviewees said that it follows that AI/AN applicants must also be receiving State medical program assistance.

In South Dakota, there are a significant number of real and perceived barriers to SCHIP, Medicaid, and Medicare enrollment – starting with the historical relationship between the State and Tribes. From the Tribes' perspective, "Anytime there is interaction between the Tribe and the State, there is conflict...and even subtle racism." As a result, "Indian people will often pull back when approached about enrolling in programs." Overall, the major barriers in South Dakota to enrolling and maintaining enrollment in State medical programs are viewed to be 1) administrative complexities; 2) perceived caseworker/agency bias; 3) lack of personalized (i.e., one-to-one) follow through; and 4) a lack of AI/AN elder-specific orientation programs providing targeted enrollment assistance services, outreach, and administrative appeals processes for Medicare.

The State's approach to managing its comprehensive social, economic, and health care service programs seems to be logical and cost effective from an organizational point of view. However, from a beneficiary point of view, it is not clear which programs he/she may be applying for, nor does the applicant know what the other programs are for which he/she may be eligible. In such a "black box," the applicant is completely dependent upon the caseworker. In some instances, the caseworker's use of "sanctions" (be they intentional or just perceived) appear to penalize beneficiary/applicants when compliance concerns predominate over an applicant's

need for medical services, neither of which promotes customer satisfaction. With the perceived focus more on compliance than access and service, AI/ANs view the State's DSS programs as, to some degree, insensitive or perceived bias.

To the State, it appears that their efforts to improve SCHIP and Medicaid programs are often unappreciated by recipients and Tribal administrations. Medicaid recipient advocates believe that State Income Guidelines are set too low; people earning minimum wages still fail to qualify in spite of their needs. Furthermore, Federal reimbursement timelines and State processing of claims do not contribute to operational efficiencies by health care providers, including direct care by the IHS. Other barriers, such as remote locations, travel distances and costs, low education and high poverty levels of applicants, and perceived physician and caseworker bias, deter enrollment.

Maximizing limited resources for IHS facilities and clinics is, in fact, an operational obligation. Failure to do so carries significant consequences for both the facility and its client base. Therefore, virtually everyone interviewed agreed that continued existence and provision of adequate health services to AI/AN people is increasingly dependent on enrollment of patients in Medicaid, SCHIP and Medicare.

Overall, most interviewees agreed that more education and outreach is essential. State officials suggested that Tribes should make greater efforts to educate and inform Tribal members about Medicaid/SCHIP/Medicare. Tribes believe the State should make greater efforts to conduct education and outreach, and to assist with enrollment processes. All agreed that more outreach and education was necessary, and that this should be designed to be understandable and usable by people who make have limited English language skills and limited literacy. In particular, the elderly often do not read well, if at all, and this makes written material of limited educational value. Therefore, enhanced educational efforts on various levels and topics ranked high in the number of recommendations for removing barriers and enhancing enrollment.

In spite of the historically strained relationship between the State of South Dakota and Tribes, site visits for this project generated as many optimistic recommendations as it did barriers to enrollment and efficient program operation. Many of the people interviewed expressed belief that there were effective approaches that could be designed and implemented to reduce enrollment barriers in all programs. Some of these strategies were on the macro level (e.g., create Tribal block grants or set-asides of Medicaid and SCHIP funds for distribution to Tribes). Others were operational and focused on systems for identifying people who were eligible through implementation of standard procedures within AI/AN health facilities and developing follow-up procedures to assist eligible people to enroll. Strategies to reduce travel and transportation barriers were also frequently mentioned.

It was also strongly recommended that the State agree to open dialogue and adopt a philosophy of "asking and not telling" what/how things needs to be done for the State's AI/AN population. Interviewees from each of the Tribes that were visited and in each of the AI/AN health facilities suggested that regularly scheduled meetings between Tribes and State officials to identify problems, raise issues, and seek to develop jointly acceptable solutions would be an important component of an effective strategy to increase Medicaid and SCHIP enrollment. Such

a change could be the catalyst for a fresh collaborative approach that could yield beneficial changes and increase trust and effective working relationships.

# APPENDIX IX.A: SOUTH DAKOTA SITE VISIT CONTACT LIST

# **Native Women's Health Center**

Name	Title	Address	Phone	
Tobianne Beauchman	Medical Records	Native Women's Health Center 2920 W. Main St. Rapid City, SD 57702	605-342-7400	nwhcnurses@rushmore.com
Patty Starkey	LPN	Native Women's Health		nwhcnurses@rushmore.com
Barbara Broomfield	Front Office Supervisor	Native Women's Health Center 2920 W. Main St. Rapid City, SD 57702	605-342-7400	nwhcnurses@rushmore.com
Francis Gray	Medical Asst.	Native Women's Health Center 2920 W. Main St. Rapid City, SD 57702	605-342-7400	nwhcnurses@rushmore.com
Sue Rooks	Certified Nurse Midwife	Native Women's Health Center 2920 W. Main St. Rapid City, SD 57702	605-342-7400	nwhcnurses@rushmore.com
Charlotte Eagle Staff Biller		Native Women's Health Center 2920 W. Main St. Rapid City, SD 57702	605-342-7400	nwhcnurses@rushmore.com

# **Crow Creek Reservation**

Name	Title	Address	Phone	
Nancy Miller	CEO	Ft. Thompson Health Care Center PO Box 200 Ft Thompson, SD 57339	605-245-1500	nmiller@abr.ihs.gov
Sherry Lulf	Managed Care Nurse	Ft. Thompson Health Care Center PO Box 200 Ft Thompson, SD 57339	605-245-1502	Not Available
Faith Alvardo	Med clerk	Ft. Thompson Health Care Center PO Box 200 Ft Thompson, SD 57339	605-245-1508	Not Available
Jackie Spier	Medical Support staff, business office	Ft. Thompson Health Care Center PO Box 200 Ft Thompson, SD 57339	605-245-1507	Not Available
Duane Big	Chairman	Crow Creek Sioux Tribe	605-245-2221	Not Available

Name	Title	Address	Phone	
Eagle		P.O. Box 50		
		Fort Thompson, SD 57339		
		Crow Creek Sioux Tribe		
Wanda Wells	Tribal Planner	P.O. Box 50	605-245-2221	wanda_w_wells@yahoo.com
		Fort Thompson, SD 57339		
Susan Smith	Crow Creek Head Start		605-245-2337	Not Available
Open meeting wit	h a group of 8 Elder	s at the Senior Center	Not Available	Not Available
Open meeting wit	h Tribal members at	the Community Center Hall	Not Available	Not Available

# Sioux San Hospital

Name	Title	Address	Phone	Email
Michelle Leach	CEO	Sioux San Hospital 3200 Canyon Lake Drive Rapid City, SD 57702	605-3552280	mleach@rapidcity.aberdeen.ihs.gov
Wendy Mesteth	Benefits Coordinator	Sioux San Hospital 3200 Canyon Lake Drive Rapid City, SD 57702	Not Available	Not Available
Debbie Mendoza	CHS/Business Office	Sioux San Hospital 3200 Canyon Lake Drive Rapid City, SD 57702	Not Available	Not Available
Colleen Steele	Business Office Manager	Sioux San Hospital 3200 Canyon Lake Drive Rapid City, SD 57702	Not Available	Not Available
Georgia Amiote	Georgia Amiote Health System Administrator		605-355-2359	Not Available

# Other Organizations

Name	Title	Address	Phone	Email
Sharon Sonnenschein	Administrator for Economic Assistance	conomic Services 700 Governors Drive		Not Available
Janet Lehmkuhl	Assistant Program Administrator Medicaid/TANF Eligibility	Department of Social Services 700 Governors Drive Pierre, SD 57501	605-773-4678	Janet.Lehmkuhl@State.sd.us
Webster Two Hawk	Commissioner	Tribal Government Relations Capitol Lake Plaza 711 East Wells Avenue Pierre, SD 57501-3369	605-773-3415	Not Available
Julie Miller	Julie Miller DSS Dist Supervisor		605-773-4776	Not Available
Donna Keeler Executive Director		South Dakota Urban Indian Health, Inc. 122 E. Dakota Pierre, SD 57501	605-224-8841	Not Available

# **Rosebud Reservation**

Name	Title	Address	Phone	Email	
William Kindle	Rosebud Sioux Tribal Council Chairman	Rosebud Sioux Tribal Office PO Box 430 Rosebud, SD 57570	605-747-2381	Not Available	
Anita Whipple	RST Health Administrator	Rosebud Sioux Tribe PO Box 719 Rosebud, SD 57570	605-747-5100	Not Available	
William Sorace	Grants Writer	Rosebud Sioux Tribe Business Office PO Box 430 Rosebud, SD 57570	605-747-4244	Not Available	
Sid Kills	RST CHR	RST CHR Office PO Box 808 Rosebud, SD 57570	605-747-2316	Not Available	
Ursula Gabriel		RST Ambulance Srvc			
L. Janine Shortbull	Ambulance staff	PO Box 200	605-747-2257	Not Available	
C. Steve Brave		Rosebud, SD 57570			
Sharon Swanson Corinne Sully	Not Available	Horizon Health/Mission Medical PO Box 49 Mission, SD 57555	605-856-2295	Not Available	

Margaret Donville	Casey Family Program	PO Box 1047 Mission, SD 57555	605-856-4855	Not Available
Patsy Kindle	DSS Social Worker	DSS Box 818 Mission, SD 57555	605-856-4489	Not Available
Clive Neiss	RST Business Office	Rosebud Sioux Tribe Business Office PO Box 430 Rosebud, SD 57570	605-747-2381	Not Available
Dale Young Deputy Service Unit Director		Rosebud IHS Service Unit Rosebud, SD 57570	605-747-2231	Not Available

## **CHAPTER X. UTAH**

#### **BACKGROUND**

#### Overview

This Case Study Report presents background information and findings from a four-day site visit to Utah conducted from October 29 to November 1, 2002. The site visit team included Kathryn Langwell and Tom Dunn of Project HOPE and Frank Ryan, J.D., a consultant to the project. The project team conducted interviews with individuals and groups at the Uintah & Ouray Reservation Indian Health Service facility, the Utah Department of Health, and the Indian Walk-In Center (Urban), located in Salt Lake City, Utah. A list of all interviewees are included in Appendix X.B.

A Draft Case Study for Utah was reviewed by the CMS Project Officer and by other CMS staff and then, after their suggested changes were incorporated, a second Draft was sent to key contacts at the State Department of Health, the Uintah-Ouray IHS, and the Indian Walk-In Center for review and comment. Follow-up telephone reminders and e-mail reminders were sent to each contact after three weeks. However, comments were received only from Department of Health staff. This Case Study Report incorporates those comments and corrections. The rationale for selecting the sites visited and description of the sites is provided in the next section, below. This section describes the American Indian and Alaska Native (AI/AN) population and AI/AN health services in Utah, as well as Utah's Medicaid and SCHIP programs and governing agencies.

The comments and recommendations contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or the feasibility of the recommendations. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services (CMS), the Indian Health Service (IHS), or the State.

# **Utah AI/AN Population and Location**

Within its borders, Utah has five Federally Recognized Tribes: 1) Ute; 2) Dine' (Navajo); 3) Paiute; 4) Goshute; and 5) Shoshoni. In 2001, Utah's total estimated population was 2,269,789, and 2 percent reported AI/AN race. About 88 percent of the State's total population is located within urban areas, with 12 percent residing in rural areas.

Table 1 below presents data from the 2000 Census on the AI/AN population residing in Reservation counties, as a percent of the total County's population. Some Reservations extend over multiple counties; the numbers below are for the County on each Reservation with the largest concentration of AI/AN residents.

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<sup>335</sup> http://dced.utah.gov/indian/Today/today.html, accessed February 13, 2003.

<sup>&</sup>lt;sup>336</sup>This 2000 statistic reflects persons reporting either one race or two or more races (http://quickfacts.census.gov/qfd/States/49000.html, accessed February 13, 2003).

<sup>337</sup> U.S. Bureau of the Census (2000),http://factfinder.census.gov/servlet/DTTable?\_ts=64250025890, accessed

U.S. Bureau of the Census (2000),http://factfinder.census.gov/servlet/DTTable?\_ts=64250025890, accessed February 25, 2003.

Table 1. Percent AI/AN Population and Median Age in Primary Reservation Counties in Utah338

	Confederated Tribes of the Goshute	Paiute	Skull Valley	Uinta Ou	h and ray	Northern Shoshoni	Navajo	Utah	US
Total AI/AN pop.	1.5%	2.6%	2.5%	10.3%	7.2%	1.4%	56.6%	2.0%	1.5%
Median age	26.5	30.3	27.1	29.0	28.3	28.0	25.5	27.1	35.3

Source: U.S. Census Bureau, Census 2000 Redistricting Data (Public Law 94-171) Summary File, Matrices PL1, PL2, PL3, and PL4.Note: Some Reservations extend over multiple counties. The data in this Table is drawn from the Reservation County that has the largest number of persons who reported AI/AN race, alone or in combination with one or more other races, on the 2000 Census. The Census Bureau had not yet released public use files providing data on Reservation populations, at the time this report was prepared, and it was not possible to construct population profiles for individual Reservations. It is anticipated that 2000 Census data on Reservation areas will be released in December 2003.

Tribal membership totals from each of the five Tribes in Utah range from several thousand to just over 100. The Goshute Indians are a small Tribe of about 125 members located on the Skull Valley and Goshute Reservations west of Salt Lake City, Utah. The (1996) Tribal population of the Shoshoni in Idaho and Utah was 383 enrolled members. As of September 1997, the consolidated Paiute Bands<sup>340</sup> in southern Utah reported a total of 709 members divided among the five Bands. The Paiute Tribe is a "young" Tribe; of the total population of 709, 47 percent are 16 years of age and younger. According to the Tribe's Department of Vital Statistics, the enrolled membership of the Ute Tribe is presently 3,120 members—eight-five percent (or about 2,650) of whom presently live within the boundaries of the Reservation. This population has grown from about 2,500 members in 1980 and is projected to increase to 4,672 by the year 2010. In comparison, the Navajo are the largest and most populous American Indian group in the United States, reporting close to 270,000 enrolled members, of which 165,614 live within the Navajo Nation borders, and about 60 percent of whom are under 25 years of age. The 2000 Census identified 14,634 Navajo members residing in Utah.

Reservations and/or trust lands for the five Tribes are widely dispersed across the State. The Goshute Reservation<sup>344</sup> <sup>345</sup> straddles the border between east central Nevada and west central Utah and the Skull Valley Reservation, with a population of 125, is just northeast of the Goshute

Source: U.S. Census Bureau, Census 2000 Summary File 1, various Matrices. http://factfinder.census.gov/bf/\_lang=en\_vt\_name=DEC\_2000\_SF3\_U\_DP3\_geo\_id=04000US49.html, accessed February 20, 2003.

http://dced.utah.gov/indian/Today/shoshoni.html, accessed February 13, 2003.

<sup>&</sup>lt;sup>340</sup> In the late 19th century, the Paiute Tribe coalesced into five Bands: the Shivwits Band, Indian Peaks Band, and Kanosh Band. Koosharem Band, and the Cedar Band.

http://dced.utah.gov/indian/Today/paiute.html, accessed February 13, 2003.

http://dced.utah.gov/indian/Today/ute.html, accessed February 13, 2003.

http://dced.utah.gov/indian/Today/dine.html, accessed February 13, 2003.

The land surrounding the Goshute Reservation has hazardous and low-level radioactive waste dumps, an electrical power plant, and a Federal Government weapons-testing site. As a historical point of interest, in the 1960's, a nerve gas accident led to the death of 6,000 downwind sheep on the Reservation.

Trust acreage for the Goshute Tribe was established under Executive Orders in 1912 and 1914. Additional land purchases were made from 1937 to 1990 for a total acreage of 122,085.

Reservation toward Salt Lake City. In 1989, the Church of Latter Day Saints granted the Northern Shoshoni Tribe 187 acres of land, located close to the northern border with Idaho that constitutes the Tribe's Reservation.<sup>346</sup> The Paiute Reservations<sup>347</sup> were established between 1903 and 1929, for all but the Cedar Band.<sup>348</sup> However, on April 3, 1980, an Act of Congress (via The Paiute Restoration Act, P.L. 96-227) recognized and restored the Federal Trust Responsibility for all five Bands, which today constitutes the Paiute Indian Tribe of Utah. The Paiute Indian Tribe of Utah is located in the corner of southwest Utah, and its service area for Tribal programs<sup>349</sup> covers a five County area. The Uintah & Ouray is the largest Reservation in the State in terms of total in-State landmass, and is located in the northeast quadrant of Utah, adjacent to Colorado. The Ute Mountain Reservation is located in the southeastern boarder of Utah and Colorado with a reported population of 277 in 2000.<sup>350</sup> The Navajo Nation covers 17 million acres spanning Arizona, New Mexico and Utah, only a small percentage of which are located in the southern half of San Juan County, Utah. A detailed description of the Navajo Reservation and Tribe, and the economic status of both will be addressed in the Arizona Case Study.

Poverty among the AI/AN population in Utah remains a pressing issue for State and Tribal officials alike. Most Indian people residing on Reservations in Utah had incomes in 1999 that were substantially lower than the Utah average. The three "poorest" Reservations in the State had an average per capita income of \$11,805 in 1999, which is 35 percent lower than the rest of Utah (\$18,185), and 55 percent lower than the United States as a whole (\$21,587) (see Table 2).

<sup>350</sup> U.S. Census Bureau, 2000.

<sup>&</sup>lt;sup>346</sup> The Bureau of Indian Affairs holds nearby privately-owned Indian lands in Trust for the Shoshoni.

The Paiute Reservation includes the Shivwits, Cedar City, and Kanosh Reservations. http://www.osec.doc.gov/eda/pdf/40Utah.pdf, accessed March 14, 2003.

The Cedar Band was ineligible for receipt of any Federal services for 26 years, as a result.

<sup>&</sup>lt;sup>349</sup> Programs offered by the Paiute Indian Tribe include Health, Social Services, Housing, Education, Alcohol and Drug, Environment, Activities, and Economic Development.

Table 2. Economic Characteristics in Primary Reservation Counties in Utah, 1999<sup>351</sup>

	Confed- erated Tribes	Paiute	Skull	Uinta	h and	Northern	Navajo	Utah	US
	of the Goshute		Valley	Ou	ray Shoshoni				
1999 Per Capita Income	\$12,790	\$13,408	\$16,321	\$13,571	\$12,326	\$15,625	\$10,299	\$18,185	\$21,587
		Percen	t Below t	he 1999 F	ederal Po	verty Level			
All Families	7.9%	9.4%	5.2%	12.0%	14.2%	5.8%	26.9%	6.5%	9.2%
Families with related children under 18 years	9.5%	13.2%	7.0%	16.2%	18.7%	7.6%	30.3%	8.7%	13.6%
Individuals 18-64:	10.0%	10.5%	6.0%	12.5%	14.8%	6.3%	31.4%	9.1%	10.9%
Individuals 65 and older:	14.5%	7.2%	7.0%	10.4%	12.4%	5.3%	29.1%	5.8%	9.9%

Source: U.S. Census Bureau, Census 2000 Redistricting Data (Public Law 94-171) Summary File, Matrices PL1, PL2, PL3, and PL4.Note: Some Reservations extend over multiple counties. The data in this Table is drawn from the Reservation County that has the largest number of persons who reported AI/AN race, alone or in combination with one or more other races, on the 2000 Census. The Census Bureau had not yet released public use files providing data on Reservation populations, at the time this report was prepared, and it was not possible to construct population profiles for individual Reservations. It is anticipated that 2000 Census data on Reservation areas will be released in December 2003.

#### AI/AN Health Services in Utah

Tribes in Utah are unique in that different portions of Utah's AI/AN population fall under the operational jurisdiction of four separate IHS Service Areas: Navajo; Phoenix; Albuquerque; and Portland. This results in many cross-border issues, which include: differing distribution of eligibility workers; jurisdictional inconsistencies; and lack of effective linkages between the States, Tribes, and IHS. These border issues become an issue when many regional Tribes (Navajo in particular) have traditional summer and winter camps that cross State boundaries (e.g., one could have a post office box in Arizona, but live half of the year in Utah).

The only direct service IHS Service Unit in the State of Utah, Fort Duchesne, is on the Uintah & Ouray Reservation, located in the northeast corner of the State. The Paiute Tribe operates the Montezuma Creek Clinic under a 638 contract and purchases all services through Contract Health Services arrangements. Services are also available to Indians who reside in Utah through a third source, the Southern Colorado Ute Service Unit, which is operated by the Albuquerque IHS Area Office and provides ambulatory care services for a field health station in White Mesa, Utah.

Source: U.S. Census Bureau, Census 2000 Summary File 1, various Matrices. http://factfinder.census.gov/bf/\_lang=en\_vt\_name=DEC\_2000\_SF3\_U\_DP3\_geo\_id=04000US49.html, accessed February 21, 2003.

Because of the size of the State and the distribution of both the AI/AN population and Reservations, many AI/ANs in Utah are required to either obtain medical services at non-IHS facilities or, in many cases, travel great distances<sup>352</sup> to obtain services at a one of these facilities.

The Fort Duchesne Health Center<sup>353</sup> is an ambulatory care, 40-hour a week facility, staffed by three physicians, one physician's assistant, and two dentists. The facility provides comprehensive health services including general medical, surgical follow-up, pediatric, prenatal and postpartum care, mental health, nutritional, substance abuse, health education and environmental health programs. Dental and optometry services are also available. Other clinical specialties are provided by visiting consultants and are scheduled periodically. After-hours and weekend coverage is handled through the emergency room at the Duchesne County Hospital in Roosevelt (8 miles away) by IHS physicians, or by local physicians on an on-call basis. Patients requiring more complex medical care are referred to the hospital or other contracted facilities.

Three physicians, one physician's assistant, and one dentist staff the Owyhee IHS facility.<sup>354</sup> This 15-bed CMS-accredited hospital provides direct medical, dental care, and emergency services. Contract health care services from hospitals and clinics in nearby towns are also coordinated. Due to the number and location of isolated communities, transportation and employment are often scarce. Staff at Owyhee attempt to reach all the people to promote awareness of programs including public health nursing, social services, mental health, nutritional, substance abuse, health education, and environmental health.

The Southern Colorado Ute Service Unit<sup>355</sup> serves the Southern Ute and the Ute Mountain Tribes and operates a field health station in White Mesa, Utah. Care includes medical, nursing, dental, optometry, nutrition, health education, community health nursing, mental health, social services, substance abuse, and environmental health services. General clinics are conducted according to a published schedule: well-child, chronic diseases, allergy, women's health, and podiatry. Pharmacy, laboratory and audiology services are also provided.

The Montezuma Creek Clinic is a community-based health center owned by the Utah Navajo Health System, Inc. (UNHS)<sup>356</sup> and operated through a 638 contract with a Navajo Tribal organization. The service area of the Montezuma Creek Clinic includes the Utah "strip" of the Navajo Nation and provides services to the un-served and the under-served population of San Juan County, Montezuma, Utah. UNHS provides medical, behavioral health and dental services for approximately 6,000 Navajo and 1,000 Anglo people.<sup>357</sup>

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<sup>&</sup>lt;sup>352</sup> Paiute Indian Tribes of Utah located on the southwest corner of the State of Utah are part of the U&O Service Unit and are over 330 miles from Ft. Duchesne.

<sup>353</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Phoenix/PxbSU Utah.asp, accessed February 13, 2003.

http://www.ihs.gov/FacilitiesServices/AreaOffices/Phoenix/PxOwyheeSU.asp, accessed February 13, 2003.

<sup>355</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Albuquerque/scusu.asp, accessed February 13, 2003.

<sup>356</sup> http://www.auch.org/health\_centers/mcchc.html, accesed June 24, 2003.

<sup>&</sup>lt;sup>357</sup> Montezuma Creek is located on the Navajo Reservation 15 miles west of Bluff at an elevation of 4,300 feet. The population is around 345 residents (http://www.pe.net/~rksnow/utCountymontezumacreek.htm, accessed March 15, 2003).

#### **Overview of Utah State Government**

The Utah Division of Indian Affairs (UDIA) was created in 1953 when the Utah State Legislature passed the "Indian Affairs Act" creating the Commission on State Indian Affairs. The UDIA has mandated functions, powers, duties, rights, and responsibilities that include.<sup>358</sup>

- Serving as the Indian Affairs authority for the State of Utah under UCA Sec. 9-1-101.
- Serving as liaison and promoting positive intergovernmental relations with and between Utah Indian Tribes (8), Office of the Governor, Federal and State agencies, and local entities.
- Coordinating with the Governor's office to address Indian Affairs' issues and develop policies.
- Coordinating with the Native American Legislative Liaison Committee to develop Indian legislation and address Indian Affairs' issues.
- Coordinating activities and working closely with two legislatively created committees: the State Native American Coordinating Board and the Native American Remains Review Committee.
- Monitoring Utah and Federal Indian legislation that impacts Utah Indian Tribes and the State of Utah.
- Developing programs and services, providing alternatives, and implementing solutions that will allow Indian citizens an opportunity to share in the progress of the State of Utah.

#### **Utah State Medicaid Program**

Administered jointly by the Utah Department of Health and the Utah Department of Workforce Services, the Utah Medicaid program is designed to pay medical bills for eligible people who have low incomes or cannot afford the cost of health care. To be considered for Medicaid eligibility, an applicant must: 1) qualify for a specific category of Medicaid, as determined by Federal regulations; 2) have resources (assets) below the Federal limit; and 3) have monthly income under the State's income standard. Each person applying for Medicaid must qualify under one of the following categories:<sup>359</sup>

- Age 65 or older
- Pregnant woman
- Child under age 18
- Legally disabled or blind
- Parent or caretaker of a child under age 19
- Woman with breast or cervical cancer

The eligibility criteria (see Table 3 below), monthly income standards, and resources limits vary, depending on the category of Medicaid and program type for which an applicant qualifies. The monthly income standard varies between approximately 100 percent and 185

<sup>358</sup> http://yeehaw.State.ut.us/yeehaw?DB2=State&T2=eutah&Query=udia, accessed March 14, 2003.

<sup>359</sup> http://www.health.State.ut.us/medicaid/SECTION1.pdf, accessed February 13, 2003.

percent of the FPL. However, applicants whose income exceeds the monthly income limit may be considered for the "Medically Needy" program. This program allows a person, who is otherwise eligible, either to pay "excess" monthly income to the State of Utah or to accept responsibility for a portion of their monthly medical bills. The resource limit also varies depending on the category of Medicaid and program type for which the applicant qualifies. The limit ranges from none for newborn children to \$2,000 for an individual, \$3,000 for two persons, with \$25 added for each additional person.

Enacted July 1, 2002, Utah's Primary Care Network (PCN) is a Medicaid 1115 Waiver that charges an annual premium (\$50 per family/household) for a select group of services<sup>360</sup> and is available to a target population of ages 19 to 64 who would otherwise not be eligible for health coverage. PCN offers an ambulatory care benefit package only (e.g., care from your Primary Care Physician; limited pharmacy; and limited dental services). In addition to the enrollment fee, PCN enrollees are also required to pay co-payments, not to exceed out-of-pocket expense of \$500 per calendar year per enrollee.

The Utah Medicaid agency contracts with managed health care organizations to provide medical and mental health services to Medicaid clients. Medicaid typically pays a monthly fee for each Medicaid client enrolled in a health maintenance organization (HMO) and/or Prepaid Mental Health Plan (PMHP). Each PCN Plan is responsible for all health care services specified in the contract for Medicaid clients enrolled in that plan. Each plan may offer more benefits and/or fewer restrictions than the Medicaid scope of benefits. It must specify services that require prior authorization and the conditions for authorization. AI/AN PCN recipients who live in rural counties are exempt from paying co-payments for services received through IHS or Tribal Health facilities. As such, AI/AN PCN recipients who live in the counties listed below are exempt from paying co-payments for services received through Indian Health Service or Tribal Health Care systems: Beaver, Box Elder, Carbon, Duchesne, Emery, Grand, Iron, Juab, Kane, Millard, Piute, San Juan, Tooele, Uintah, and Washington. However, it is important to note that fifty percent of AI/ANs in Utah live either in or surrounding the urban area of Salt Lake City. 

1. \*\*Control of Carbon\*\*

2. \*\*Control of Carbon\*\*

3. \*\*Control of Carbon\*\*

Another medical assistance program is "Newborn Medicaid" which is designed for children from birth to age six. Program flexibility specifies that the child's mother need not have been on Utah Medicaid in the month of birth in order for her child to qualify for this program. The income limit, after allowable deductions, is 133 percent of the FPL, which is typically adjusted annually. The Aged, Blind or Disabled Programs are medical assistance programs for individuals aged 65 years or older, blind, or disabled. Persons who receive Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) benefits meet the conditions for disability. For other persons to qualify on the basis of blindness or disability, the person must have a physical or mental impairment which either (1) can be expected to result in death or (2) lasts for not less than 12 months. The impairment must be of such severity that the person is unable to do his or her previous work and cannot (considering age, education and work experience) engage in other kinds of substantial, gainful work. The income standard, after

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<sup>&</sup>lt;sup>360</sup> Inpatient services are excluded from this package.

<sup>&</sup>lt;sup>361</sup>http://sitedir.State.ut.us/om\_nsapi.oms?clientID=408512&advquery=910-1&infobase=vol-3f.nfo&record={9155} &softpage=Browse Frame Pg42&zz, accessed March 7, 2003.

<sup>&</sup>lt;sup>362</sup> Information provided by Balerma Burgess, Indian Health Service.

allowable deductions, is based on a percentage of the financial assistance grant level, as determined by the Utah State Legislature.

Most Medicaid programs allow an applicant to request coverage for medical services for up to three months prior to the month in which the person filed a Medicaid application. A person who received medical, dental or mental health services and subsequently qualifies for Medicaid may return to each provider with a Medicaid Identification Card for the month in which service was provided. A provider may subsequently choose to accept Medicaid as payment in full for services already rendered or refuse to seek Medicaid payment because the patient had not been determined eligible for Medicaid at the time of service. If the provider accepts Medicaid, Medicaid will pay for the service; otherwise, patients are responsible for charges.

Redetermination of eligibility for Medicaid family programs is required every six months. Elderly Medicaid recipients, however, are required to undergo redetermination on an annual basis.

Table 3: Utah Monthly Medicaid and SCHIP Income Eligibility Standards, 2003

Household Size	Medicaid** (BMS programs) <sup>363</sup>	Primary Care Network* <150% FPL	Medicaid <sup>364</sup> 100% - 133% FPL*	Transitional Medicaid 185% FPL*	CHIP Plan A* 150% FPL	CHIP Plan B* 200% FPL
1	382	1,108	739982	1,366	1,108	1,477
2	468	1,493	9951,324	1,841	1,493	1,990
3	583	1,878	1,2521,665	2,316	1,878	2,504
4	882	2,263	1,5092,007	2,719	2,263	3,017
5	777	2,648	1,7652,348	3,266	2,648	3,530
6	857	3,033	2,0222,689	3,741	3,033	4,044
7	897	4,188	2,2793,031	4,215	3,418	4,557
8	938	4,573	2,5353,372	4,690	3,803	5,070
9	982	4,188	2,7923,713	5,165	4,188	5,584
10	1023	4,573	3,0494,055	5,640	4,573	6,097

<sup>\*</sup> If over income limit, spend down is allowed.

Note: Deduct \$90.00 from the countable earned income of each working family member, as well as childcare expenses, health and accident premiums. Deduction of \$30.00 plus one-third of working income may be allowed only if a client has received this deduction under a type of Family cash assistance in one of the last four months. Source: Utah Medicaid Eligibility Manual, Volume III-F, January 2003 Update.

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<sup>\*\*</sup> If over income limit, spend down is *not* allowed.

<sup>&</sup>lt;sup>363</sup> Eligibility for this category of Medicaid is *not* based on FPL; instead, it is based on "Basic Maintenance Standard" (BMS), which is a fiscal term to balance the amount of available revenue with how many people can participate in any give budgeting period – normally, this is the State fiscal year. BMS programs include: CM: Children Medical, also know as Medically Needy Children; FM: Family Medical, includes children and parents if they meet deprivation; PG: Is an old Pregnancy program, which allows a "spend down" where the PN (Prenatal) does not; RM: Is Medicaid for Refuges; AM: Aged Medical for those 65 and older; BM: Blind Medical for those who are blind; and DM: Disabled Medical for those who meet disability criteria.

<sup>&</sup>lt;sup>364</sup> Income eligibility standard varies depending on eligibility category.

#### **Utah SCHIP Program**

Utah's SCHIP<sup>365</sup> is a "separate" child health program administered by the Utah Department of Health. Health services in the urban areas (Davis, Salt Lake, Utah, and Weber counties) are delivered by managed care organizations. The State currently contracts with six Managed Care Organizations for their Medicaid population. Health services in rural areas (all other counties) are delivered by providers on a fee-for-service basis. Depending on the income level of the applicant, there are two levels of SCHIP: Plan A and Plan B. Both plans offer identical benefits. The only differences between the two are the quarterly premiums (Plan A is \$13 and Plan B is \$25) and co-pays.

The State reported that 34,655 children were enrolled in its SCHIP program during Federal fiscal year 2001.<sup>366</sup> However, according to a recent report by the Urban Institute, there are 39,500 eligible for SCHIP or Medicaid in Utah but not enrolled.<sup>367</sup> On March 1, 2002, Utah submitted an amendment to CMS that would allow the State to establish the following: 1) an enrollment cap of 24,000; 2) require premiums and increased co-payments for enrollees above 100 percent of the FPL; 3) disregard the child's income when determining family income; and 4) modify the dental, vision, and hearing services within the benefit package. Cost sharing was also modified in this amendment to require:

- Effective January 1, 2002, co-payments for families with income 101 percent or more of the FPL for most services were increased.
- Effective July 1, 2002, families became subject to premiums of \$13 per family per quarter for Plan A enrollees and \$25 per family per quarter for Plan B enrollees.

After approval, the Utah Department of Health implemented the following changes<sup>368</sup> to SCHIP, effective in 2002:

- Only preventive and emergency dental procedures are covered, effective January 1, 2002. The SCHIP program will cover dental procedures that have been started as part of an ongoing course of treatment. Preventive care includes exams, X-rays, and cleanings.
- Changes in co-payments that took effect in January 1, 2002 include cost sharing up to a maximum of \$13-\$25 per family every three months (depending on family size and gross monthly income). The total out-of-pocket cost for a family on SCHIP is limited to no more than five percent of the family's income.

http://health.utah.gov/medicaid/html/managed care.htm, accessed February 13, 2003.

http://www.cms.gov/schip/chpfsut.pdf, accessed March 14, 2003.

<sup>&</sup>lt;sup>367</sup> The Urban Institute, 2002. *Released August 1, 2002*. Based on merged March 2000 and 2001 Current Population Survey data, weighted to represent one year, with adjustments for reported changes in Medicaid and SCHIP as of December 2001.

http://health.utah.gov/chip/benefitreductions.htm, accessed March 14, 2003.

#### DESCRIPTION OF SITE VISIT

#### Overview

Before conducting the site visit to Utah, the site visit team contacted Jim Lyons, the CMS Native American Contact for Region VIII, to identify local contacts in Utah with whom we could discuss the Tribes and Reservations within Utah, as well as urban Indian health facilities, that would be selected for site visits. Mr. Lyon provided invaluable background information and directed us toward individuals who would be of assistance. Further advice and suggestions were obtained from Judy Edwards, Tribal Liaison for the Utah Department of Health, and from the Director of the Diabetes Program for the Uintah and Ouray Reservation. For each of these discussions, the project team provided individuals with a copy of the project description and summary of the goals of the site visits. Respondents were asked to identify specific Reservation, urban facilities, and others who would be appropriate to interview in Utah. The project team also emphasized that, given that only three days were budgeted for the site visit, travel distances were also of some importance.

Based on these discussions and the recommendations received, the project team selected the Uintah and Ouray Reservation in northeast Utah and the Indian Walk-In Center in Salt Lake City as sites for the Utah interviews. In addition, the project team arranged meetings with the State Tribal Liaison, Utah Department of Health management staff, and members of the Utah Tribal Health Board.

The process for recruiting participation in the site visit consisted of the following steps: 1) a letter was sent to the Tribal Chairmen at Uintah & Ouray Reservation to inform them of the study and that their Tribe had been selected to participate; 2) follow-up telephone calls to the Tribal Chairmen were made to confirm their willingness to participate and to identify a coordinator from the Tribe to assist in scheduling and coordinating the site visit; 3) the project team then worked closely with the Tribal coordinator to determine the individuals who would participate in the scheduled meetings and to obtain background information on unique issues and programs at each site; and 4) a formal agenda was developed for each site visit. We followed a similar process for the Salt Lake City urban Indian health facility. The State Tribal Liaison assisted the project team in scheduling meetings with State Department of Health staff and worked with the Utah Tribal Health Board to arrange for the project team to have time on their monthly meeting agenda. A complete list of individuals who were interviewed during the site visit is provided in Attachment X.A to this report.

# Description of the Ute Tribe and the Uintah and Ouray Reservation<sup>369</sup>

The Ute Indian Tribe is made up of three bands: the Uintah; the White River; and the Uncompangre. The Uintah and Ouray (U & 0) Reservation is located within a three-County area in Northeastern Utah, covering a large portion of western Uintah and eastern Duchesne Counties. Despite the size of the Reservation, Utes comprise only 7.4 percent of the populationTribal population has grown from about 2,500 members in 1980 to 3,120 in 2000 and is projected to

<sup>&</sup>lt;sup>369</sup> The Northern Utes of Utah (http://historytogo.utah.gov/nutes.html, accessed February 26, 2003).

increase to 4,672 by the year 2010. Eight-five percent (or about 2,650) presently live within the boundaries of the Reservation.

Today's surface ownership of the Uinta Basin is a mixed tapestry of Federal Lands (50.5 percent), Fee Lands (23.8 percent), Tribal Trust Lands (17.5 percent), and State of Utah Lands (8.2 percent). The Ute Tribe, with slightly more than one million acres, has ownership of almost one-quarter of the Uinta Basin's total land area. However, the ownership of the surface does not necessarily mean ownership of the minerals—i.e., a large area of land, known as the Hill Creek Extension, is Tribally owned with mineral rights being owned by the Federal Government.

# Description of Utah Indian Walk-In Center, Salt Lake City—Utah Urban Area

The Indian Walk-In Center (IWIC) is a non-profit 501(c)3 entity, established in 1984, that provides services in and around Salt Lake City and the Wasatch Front for approximately 35,000 AI/ANs and other low-income residents. IWIC provides services to clients from numerous ethnic backgrounds, as well as to members of more than fifty separate Tribes. IWIC's services include: emergency assistance, food pantry, social/cultural activities, health care services, family counseling, dental services, and alcohol abuse services. Health care services are not provided at the IWIC facility, but are arranged through a contract with a local Community Health Center. IWIC purchases a block of scheduled time for a fixed price at the Health Center and then schedules appointments for patients during the set-aside hours. The IWIC receives operational funding through a variety of sources, including the United Way, IHS, and donations from private companies.

## FINDINGS: UINTAH & OURAY RESERVATION

## <u>Overview</u>

The State Tribal Liaison provided contact information for the Ute Tribe's Health Director, who is also a member of the Utah Tribal Health Board. Over the course of several weeks, the project team and the Tribe's Health Director had several discussions regarding the purpose of our visit, with whom we wanted to meet, and the type of information we sought. Following these discussions, a meeting with key IHS staff and with several Tribal members, including the Community Health Representative Director, the Director of the Tribal Diabetes Program, and the Director of the Senior Center was arranged. In addition, the Department of Health Supervisor from Provo, Utah, traveled to Fort Duchesne to participate in the meeting.

# Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Ft. Duchesne has the State's only IHS direct service clinic. The Tribes in Utah are under the jurisdiction and management of four overlapping IHS Area Offices, a fact that reportedly compounds the challenges of outreach, enrollment, and delivering health care services to a small population dispersed over a large, rural geographic region. The number of people using IHS services has grown in recent years.<sup>371</sup> Ninety percent of the user population growth is local,

<sup>370</sup> http://dced.utah.gov/indian/Today/ute.html, accessed March 14, 2003.

<sup>&</sup>lt;sup>371</sup> Fort Duchesne IHS Service Unit data on patients using services, cited by IHS staff.

while ten percent is due to an increase in the number of urban residents who come to the Reservation for services. The current user population at Ft. Duchesne is less than 5,000 and, of that total, 6 to 7 percent are currently enrolled in Medicaid (even fewer are on Medicare). At one time, the proportion enrolled in Medicaid and Medicare was reportedly close to 19 percent, "but has since dropped off." IHS interviewees represented these estimates as "best guesses" and acknowledged that they do not have firm data on the number of users who are enrolled in these programs.

Interviewees said that one possible reason for a decline in enrollment is that Tribal members may fail to apply for or comply with redetermination requirements once they obtain employment, believing that if they have any income they are no longer eligible for Medicaid. This is particularly problematic since Tribal members who want Contract Health Service approval are required to apply for Medicaid and SCHIP and do not receive approval unless they can show evidence that they have applied and been approved or rejected. If members stayed on the programs for as long as they were eligible, they would not have to go through the time-consuming process of applying over and over again to see if they qualify for Contract Health Services. The decision would be more straightforward; if they are on a program, they do not qualify and if they are no longer on the program because of income limitations, they would most likely qualify for Contract Health Services. This would save the time of Contract Health staff as they would have a more targeted population with whom to work.

Although Tribal leaders earlier testified before Congress endorsing the SCHIP concept, the Tribe is now "very disappointed". SCHIP enrollment is currently closed, except for infrequent open periods. Compounding this disenchantment, the IHS facilities cannot receive reimbursement for services rendered to children enrolled in SCHIP because a "participating agreement" with the State has not yet been signed. At this point, it is uncertain where the responsibility lies to resolve this ongoing matter.

In addition, interviewees said there are continuing jurisdictional inconsistencies between CMS, IHS, and the State, and that these inconsistencies work against enrollment. Also, there is a hesitancy on the part of State and Federal policymakers to make defining decisions when ambiguity within the Federal programs is detected. An ensuing State of paralysis then seems to affect policymakers, thereby forcing potential program applicants to wait until someone at the State, IHS, or CMS makes an effort to resolve the issue. Despite the complexities and multijurisdictional issues, interviewees did say that the State Medicaid Office has worked well with the Tribe and IHS on enrollment issues and resolving problems that arise. The Health Program Specialist at the Ft. Duchesne Service Unit is a State employee and has been assigned to work at the Service Unit to assist people with Medicaid and SCHIP eligibility determination, enrollment, and redetermination issues.

# Barriers to Initial Enrollment

Interviewees most frequently reported the following barriers to enrollment in Medicaid and SCHIP:

• Tribal leaders are not supportive and do not take a leadership position to encourage members to enroll in Medicaid and SCHIP. IHS staff and administration said they have

made personal contacts with Council members about the enrollment problem, but currently "there isn't much support from the Tribe on this issue." Furthermore, Tribal leaders publicly State that IHS is responsible for health care and that it should not be necessary for Tribal members to enroll in State/Federal programs.

- There are two significant problems with the Medicaid PCN program that affect enrollment. First, there is an annual \$50 dollar "Enrollment Fee," and most Indian families cannot afford this fee. Second, the term "Enrollment Fee" prevents the IHS from paying the fee for eligible users. If it were called a "Deductible," the IHS could pay the fee for enrollees. However, the State did not consult with IHS before introducing this new charge.
- All Individual Indian Monies (IIM) are currently "closed down" due to the controversy and legal situation surrounding the U.S. Bureau of Indian Affairs management of Tribal Trust Accounts. However, when these monies had been disbursed in the past, some eligibility workers (and Tribal members) were not aware that these funds could not be counted as taxable income for Tribal members; applicants have been disqualified from Medicaid and SCHIP as a result.
- "To some degree," there is State/Tribe collaboration. Interviewees said, however, that Tribes are often "told," rather than consulted, of new policies that impact Indian people. Tribes are called in at the last minute when it is already "too late" to modify policy parameters and implementation plans.
- There are there not enough eligibility workers to assist Indian people who may be eligible. In addition, interviewees said that there is insufficient training of eligibility workers on the unique rules that affect this population.
- Interviewees stated that the major flaw in the system is having one Federal agency CMS paying another Federal agency, IHS, through a State agency, especially when the "flow through" is 100 percent. An IHS facility in Utah that provides services to a Nevada Indian cannot receive reimbursement from the Nevada IHS facility, much less recover from the State of Nevada for Medicaid reimbursement, without an agreement.

#### Barriers to Maintaining Enrollment

• IHS users resent the time taken to update third-party information and complain about it. In the past, all patient files were updated for third-party information each time an individual visited the Service Unit. This protocol was helpful in keeping files up to date and assisting people with enrollment and redetermination. Because of complaints, however, updates are now done only every three months.

# Current Enrollment and Barriers to Enrollment in Medicare and Medicare Savings Programs<sup>372</sup>

One of the overarching barriers facing elders in terms of enrollment is that they do not understand Medicare in general and program communication materials are not well written. There is little information on Medicare and Medicare Savings Programs appropriate for AI/ANs that is accessible and understandable to this population.

Interviewees identified three additional barriers to enrollment:

- The Social Security worker comes to Ft. Duchesne only once a month, for one hour. With such limited assistance, few people who are eligible for SSDI (and subsequently Medicare) can be provided with the help that they need to apply (and re-apply) for SSDI.
- Elders typically wait for the Health Program Specialist to personally answer their questions, even if a 1-800 number (for questions and other assistance) is specifically provided on the Explanation of Medicare Benefits (EOMB) and/or various form letters.
- The Medicare Part B premium is a financial deterrent to enrollment of many elders, especially those with low incomes.

# Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

Successful partnerships with women and grandmothers on Reservations can have a positive effect on enrollment in Medicaid, Medicare and SCHIP. Interviewees stated that, in most Native American cultures, women and grandmothers play a major role and are the objects of respect within their communities and Tribes. This is a cultural fact that has been largely untapped in terms of outreach efforts. To increase participation in State and Federal programs that focus on health issues, concentrated efforts should be made to win the endorsement of women and grandmothers. Other targeted strategies that were suggested by interviewees include:

- Waive or eliminate enrollment fees, premiums, and co-payments for AI/AN people eligible for Medicaid.
- More outreach and education on Medicaid, SCHIP, and Medicare is essential. This information should be specially developed and culturally appropriate for Indian people. It is especially important that this outreach and education include information to dispel "myths" about these programs that dissuade people from applying for enrollment. Outreach and education should be conducted by State and Federal agencies and by Tribal leaders and health directors, both independently and collaboratively.

Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWID) programs. Medicare Sovings Programs enrolleds together with

- Place staff out in the field to conduct focused outreach and enrollment assistance. Increasing enrollment in these programs requires personal one-to-one assistance to be effective.
- **Bilingual outreach and education workers.** Outreach and education workers also should have bi-lingual capabilities, since many elders do not speak or understand English well.
- Routine placement of State enrollment workers on Reservations and in IHS Service Units. Fort Duchesne's Health Program Specialist is a State employee, and is very helpful in providing program orientation training and application assistance.
- Elimination of Federal Medicaid payments to the State. Such payments should be made directly to each IHS facility. The State should have no vested interest in managing these funds
- Increased coordination and consultation on Medicaid and SCHIP issues between the State and the Tribes
- **Tribal endorsement of enrollment in programs**. A more active role on the part of Tribal leaders and other respected Tribal community members in educating Tribal members about health issues and the benefits to all Tribal members of enrollment of eligible people in Medicaid, SCHIP, and Medicare.

## Other Issues

Interviewees also raised a fundamental question: Why does CMS prefer the State of Utah to determine the eligibility of Indians for Medicaid when services under these programs are provided by another Federal agency (the IHS) and no State dollars are required to pay for these services? IHS has the capability to make eligibility determinations, based on State and Federal guidelines. If the IHS (or the Tribes) had the authority and responsibility for eligibility determination, then the administrative fee that the State receives for eligibility and enrollment functions could, instead, be directed to IHS or to the Tribe to use for enrollment outreach and assistance.

#### FINDINGS: SALT LAKE CITY URBAN INDIAN HEALTH FACILITY

#### Overview

The Executive Director, Gail Russell, the Development Director, and Administrative Assistant of the Indian Walk-In Center (IWIC) in Salt Lake City met with the site visit team. They explained that funding for the IWIC comes from a broad range of contributors. The Church of Latter Day Saints provides limited funding and services for the IWIC, but carries with it a stipulation that assistance can only be provided for two-parent families when the parents are legally married. While the Federal government provides millions of dollars to on-Reservation Indians in Utah, they are far less generous in providing funds for health care and other services needed by Indian people who live in urban areas. Only 32 percent of Utah's AI/AN populations live on Reservations. The Federal government provides annual funding to the Walk-in Center of

\$340,000, yet the Center is responsible for providing services to approximately 50 percent (18,000) of the AI/ANs in Utah. Based on this example, and a long history of other such inequities, it was stated that "Indians mistrust the Federal government – and for good reason."

IWIC staff believe that there are probably more AI/ANs eligible for Medicaid and SCHIP than are actually enrolled. "Navajo are particularly hesitant to enroll," but the reason(s) for this phenomenon are unknown. Interviewees also said that many Indian people are not aware that they may be eligible for Medicaid, SCHIP, and Medicare (as a result of inaccurate stories spread through word-of-mouth), so they do not even try to apply. Staff at the Walk-In Center continually address many programmatic misconceptions and, therefore, are constantly engaged in program education efforts.

Upon the initial announcement of SCHIP, IWIC staff were very excited and contemplated how to get as many Indian children enrolled as possible. They asked the State to allow on-site eligibility determinations at their facility, and the State accommodated this request. The Walk-In Center now has an eligibility worker on site one-half day a week (she "has done a tremendous job"). This individual does face-to-face application assistance and is very good at making callbacks — a critical function for successful enrollment. She works with Community Health Centers (CHCs) to design posters (Medicaid, SCHIP and the Primary Care Network) specifically targeting American Indian people. IWIC also has a bi-lingual Navajo on staff and, at one point, also offered the services of a bi-lingual paralegal. Access to legal advice was invaluable in assisting the American Indians who are disabled and eligible for SSDI and Medicare. This individual has since entered law school and current applicants are referred to Utah Legal Services for assistance. Most clients at the IWIC are repeat customers. Those that are new are screened for eligibility and enrollment in assistance programs. Those not yet enrolled are referred to the front desk for information and application assistance.

In the past, AI/AN clients did not need an appointment to receive services at the CHCs in Salt Lake City. However, the large number of people – both Indian and non-Indian – needing services overloaded the ability of CHCs to provide timely and efficient care. IWIC now has negotiated a subcontract arrangement for a specific number of "slots" at a CHC for AI/AN clients. They are only provided services with a formal referral from IWIC.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

IWIC staff believe that more urban Indians are eligible for Medicaid and SCHIP than are enrolled. They also said that it is their perception that Navajo people are less likely to enroll in these programs than are AI/ANs from other Tribes.

#### Barriers to Initial Enrollment

Barriers to enrollment that were identified by the IWIC interviewees include:

- Navajos were reported to be "more reluctant" to enroll because of "past denials."
- Interviewees also stated that, in order to receive services from Federal and State programs, AI/ANs are required to prove that they are members of an AI/AN Tribe. This

was described as inequitable and discriminatory since members of other minority populations are not required to prove their heritage.<sup>373</sup>

- The State PCN program requires an annual \$50 dollar "enrollment fee" that is a significant financial barrier for many AI/AN families. At IWIC, corporate donations are available to pay this enrollment fee for AI/AN clients but there may be others who are not aware that this assistance is available and do not seek to enroll because of the fee.
- Often, eligibility workers do not take the time to adequately educate AI/AN clients about Medicaid and SCHIP. This could be due to time constraints and/or the fact that workers are, in many cases, unfamiliar with the concept/system of access to health and social services on the Reservation and how different it is for AI/ANs.
- For AI/AN people living on the Reservation, there is no urgent need to enroll in programs to receive medical services since they are available through an IHS facility, and the issue of being billed for such services is even more unfamiliar.
- It is important that AI/AN people living off the Reservation understand the alternatives that are available to them for health care, including Medicaid and SCHIP programs.
- Education and outreach programs are not designed for people with low levels of literacy and/or limited facility with English. Many AI/ANs in Utah have little education and their first language is not English. In addition to a lack of awareness of programs, these limitations make it very difficult for people to complete the complicated enrollment forms and to understand and respond to written communications from the State about eligibility status and redetermination requirements.

## Barriers to Maintaining Enrollment

• Eligibility and program workers do not routinely explain to AI/AN people who are transitioning out of State welfare programs that Medicaid or SCHIP coverage is still available to them. As a result, these individuals lose coverage and do not re-apply because they assume they are no longer eligible.

## Current Enrollment and Barriers to Enrollment in Medicare and Medicare Savings Programs

IWIC interviewees believe there is probably under-enrollment of eligible AI/ANs in the Medicare and Medicare Savings Programs. The barriers to enrollment in Medicare Savings Programs were identified as similar to the barriers to enrollment in Medicaid and SCHIP.

• Interviewees said that they give little effort to identifying eligibility for Medicare or to encouraging people to enroll because, for the most part, they and their contracted medical providers are not able to bill Medicare for services.

<sup>&</sup>lt;sup>373</sup> It appeared that the interviewees were referring to requirements for proof that an individual is a member of a Federally Recognized Tribe, which would only be necessary for services at an IHS facility.

- The complexity of the Medicare process and program. It is hard to provide information and outreach when the process is complicated and when there are no funds to support needed educational efforts.
- Social Security is "well-known" for automatically denying "every disability application."
   Utah Legal Services does help people with their Social Security Disability applications
   but the process remains very complicated. Venting their frustration with the entire
   process, IWIC staff said that an applicant should not need to hire a lawyer to overcome
   automatic denials.

## Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

- Universal healthcare for AI/ANs. One suggestion put forth was for the Federal government to provide all AI/ANs with a personal universal health care card. This individual was of the opinion that AI/ANs should not have to apply to the State for health programs because of the Federal Trust Responsibility.
- Provide focused training to eligibility workers on issues unique to the AI/AN community.
- Increase efforts to hire AI/AN eligibility workers.
- Facilitate and encourage Tribes to fully administer their health programs, including responsibility for (and funding for) outreach and enrollment programs.
- Better training for eligibility workers on availability of program for those transitioning off of welfare programs. Train eligibility workers through the State to provide accurate information about continuation of Medicaid coverage and availability of SCHIP coverage for people that transition off of State welfare programs.
- Fund onsite eligibility workers at the IWIC and other urban Indian facilities. These individuals would be responsible for conducting enrollment outreach, application assistance and follow up, and for assisting with problems that arise.
- Waive or secure private funding to pay the \$50 PCN enrollment fee for AI/AN people.

#### FINDINGS: UTAH MEDICAID AGNECY OTHER STATEWIDE AGENCIES

## Utah Department of Health, Utah Tribal Health Board

The project team met with several members of the Utah Department of Health staff and the State Tribal Liaison in Salt Lake City. This meeting was scheduled to coordinate with the monthly meeting of the Utah Tribal Health Board.

## Overview

The State Department of Health (DOH) staff were uncertain whether there was underenrollment of AI/ANs in the State Medicaid, SCHIP, and PCN programs. However, they stated that efforts had been made to increase enrollment of this population, including designating 10 percent of Medicaid administrative match funds to outreach and enrollment to AI/AN populations in the State. DOH had also developed a program to use "fee agents" to assist AI/AN people with the enrollment processes. This concept, modeled after Alaska's program, was designed to train individuals to assist people to complete enrollment forms and paid a fee to the agent for each completed application. The program proved unsuccessful (it reportedly flew like a "lead balloon"). The primary problem was that the Tribes did not like non-Tribal individuals receiving remuneration for this activity. The Tribes felt the funds should be distributed to the Tribes to provide this assistance. (In fact, the matching funds do go to the Tribal facility conducting the Medicaid/SCHIP outreach and enrollment assistance). The State would not agree to this demand, stating that they needed to maintain control over the training for fee agents.<sup>374</sup>

Both State staff and Tribal Health Board members said that outreach and enrollment is especially needed to overcome inaccurate programmatic "perceptions" among AI/AN people in Utah. One of the more pervasive perceptions is the AI/AN belief in an undercurrent of secrecy among State workers when it comes to sharing program eligibility and enrollment information. Many AI/ANs believe that unless one asks the *right* question in the *right* sequence, information will not be volunteered or forthcoming. As one example, a Utah Tribal Health Board member said it took her two to three years to develop a relationship with several State agency officials whereby program information was shared *without prompting*. Yet, few of her Tribal members receive this level of service and information. She said AI/AN people should not have to conduct an informational treasure hunt just to hear all their options. For instance, the worker should say, "Although you don't currently qualify for XX, because of XX, here are some programs for which you do qualify."

It was also generally agreed by members of the Tribal Health Board that more training for eligibility workers was necessary if accurate information and appropriate enrollment assistance were to be provided. Workers (reportedly) do not fully understand all the regulations unique to the AI/AN population (when asked to substantiate this Statement, no evidence was provided). The State was quick to respond to this charge and stated that if they ever hear of such a problem, they resolve it quickly. Tribal Health Board members also felt that State eligibility workers should change their focus from "who shouldn't receive services" to "what are all the programs an applicant might qualify for." In addition, Health Board members suggested that some eligibility workers go out of their way to make Medicaid/CHIP enrollee/applicants feel "guilty" for applying and/or being enrolled, e.g., one worker told an AI/AN client that if they can afford to eat out, ever, then they have no right being on SCHIP.

State staff also stated strongly that CMS policies and operational decisions about the 100 percent Federal match for services provided to AI/AN Medicaid enrollees was a major issue for State Medicaid programs. At present, the CMS rules permit the 100 percent Federal match only if services are provided by IHS "inside the building" – other services, even if provided by IHS, receive only the normal Federal match rate. State staff suggested that States would be more

<sup>&</sup>lt;sup>374</sup> The State responded to this issue that, from their perspective, the problem was not in using non-Tribal members, but in how Tribal members acting as fee agents should be paid, either directly by the State or through the Tribal health program. The State felt that the payment should go to the Triba and the incentive given as part of the employees' job performance. The Triba wanted the person paid directly but that would have set them up under contract with the State for the same job the Triba was paying them for. While the State is still open to the idea, a solution to the conflict has not found.

likely to aggressively conduct outreach and enrollment of AI/AN eligible people into Medicaid if CMS would provide 100 percent match for all services provided to AI/AN enrollees – regardless of site or type of service.

## Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

State staff and Tribal Health Board members also noted the following barriers:

- Many AI/AN people and Tribal leaders, in particular, do not believe that AI/AN people should be required to enroll in Medicaid and SCHIP in order to receive health care, since health care is a Federal Trust Responsibility.
- There is inadequate understanding of the benefits to individuals and Tribes in general of enrollment in Medicaid and SCHIP.
- Many AI/AN people have little education and/or do not speak English as their primary language, which makes written materials difficult to understand and to complete.
- There are too few eligibility workers to meet the needs of all the people who require assistance.
- Training of eligibility workers may be inadequate to ensure that they are fully knowledgeable of issues that are unique to AI/AN people and that affect their eligibility for Medicaid and SCHIP programs.
- In most cases, State agency staff are prohibited from speaking with anyone except the client/enrollee. Although the issue of confidentiality was acknowledged, there are times when a client needs an advocate to accurately respond to agency questions. This "rule" is perceived as a barrier to enrollment/re-enrollment, especially for a population whose culture seems to interpret any barrier as "a denial."
- The paperwork that is required for the various programs for which people may be eligible is excessively burdensome and duplicative.
- The \$50 Enrollment Fee for the PCN program is a significant financial deterrent to enrollment for many AI/ANs.

## Barriers to Maintaining Enrollment

- Transportation barriers are a serious problem in Utah for AI/ANs, particularly in remote areas. People may have to travel many miles to apply and go through eligibility determination. They then, once enrolled, are required to attend an in-person orientation meeting before they are eligible to receive services.
- There is little follow-up and outreach to assist people with redetermination. If someone does not bring in verification documents for one program (e.g. food stamps), they may

lose all benefits for all programs. There also is inadequate understanding of the relationship between TANF and Medicaid. Someone who transitions off TANF is able to continue receiving Medicaid for a time (and also has SCHIP and PCN program options). However, many people do not understand this and assume that they cannot continue in Medicaid.

## Current Enrollment and Barriers to Enrollment in Medicare and Medicare Savings Programs

The State said that the IHS clinic staff fully understand the advantage of billing Medicare for services. In addition, both the State DOH staff and Tribal Health Board members said that many AI/ANs have little knowledge and understanding of the Medicare program. Barriers to enrollment in Medicare and in Medicaid Savings Programs are, in general, the same as the barriers to enrollment in Medicaid. Additional barriers to enrollment in Medicare include:

- Some people may not know that they are enrolled in Medicare Part A, even though CMS sends a letter informing them of their coverage. Literacy, language barriers, and lack of knowledge of Medicare are barriers to Medicare program use.
- For SSDI applicants, it is not culturally appropriate to hire an attorney (even if the applicant could afford one) to contest a denial, resulting in lower than expected enrollment for otherwise qualified individuals.
- The paperwork associated with application for SSDI is "overwhelming" and many people are not able to complete the application form without substantial assistance.
- The apparent inconsistency between those who are documented as disabled and those who have been denied creates frustration and a pervasive sense of mistrust about both the application process and the program in general. One Tribal Health member said she is often surprised to see the wide disparity between those who are mobile and mostly functional and determined eligible for SSDI, and those burdened with far greater disabilities who are still fighting to be qualified as disabled.
- The Medicare Part B premium is a significant financial deterrent to enrollment in Part B for many AI/AN elders and people with disabilities.

## Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

One of the more global recommendations suggested was to organize and host another "Western Summit on Health Care." Although this has not been held for the past three years, its value has not diminished and the Tribal liaison would like to see it re-convene. This meeting was organized as a two to three day event, with collaboration between the Utah Department of Health

and the Western Governors Association, to discuss and address a broad range of Federal-State-Tribal issues.<sup>375</sup> Other Utah-specific suggestions were:

- Increase the number of eligibility workers. It would be helpful if more eligibility workers could be placed on Reservations and in IHS facilities to increase accessibility and reduce transportation barriers.
- Hire more eligibility workers who are AI/AN and who may be more effective, on average, in working with AI/AN people.
- Tribal leaders and community members should be better informed on the benefits to the Tribe of enrolling people in these programs. They should take a leadership role in encouraging and supporting people to enroll.
- Increased cooperation and collaboration among the Tribes, IHS, and the State. This could be an effective strategy to encourage and increase enrollment.
- Place a secondary address of the IHS facility on Medicaid and SCHIP enrollees' records and send redetermination letters to both addresses. This would enable IHS to follow-up and assist people in completing the redetermination process.
- Radio is the most effective communication channel to reach AI/AN communities with messages about Medicaid, SCHIP, and Medicare, followed by local newspapers. More outreach and education activities should be conducted using these media.
- Enhance outreach to elders. Elders need more outreach resources and educational materials to explain the differences between, and functions of, Medicare Parts A and B. It is important that these materials be available in forms other than written and that they be available in native languages. For example, the State of Utah produced a video in the Navajo language on why and how to enroll in Medicaid, SCHIP, and Medicare.
- **Develop a Medicare "fact sheet"** to: 1) dispel persistent myths about eligibility and enrollment; and 2) highlight the most significant benefits of enrolling to the individual, Tribe and IHS facilities. A caveat should be noted: it was stated that many people simply do not read mailings (i.e., informational material) from the State and Federal government.

#### **DISCUSSION**

Utah is unique among the 10 States in which site visits were conducted, in several ways:

- It has the smallest AI/AN population among the 10 States.
- The AI/AN population is very dispersed.

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<sup>&</sup>lt;sup>375</sup> Comments on an earlier draft of this Report by State staff noted that none of the strategies suggested included a "Federal response" for improving utilization (with the exception of recommending another Western Summit on Health Care), nor was there any general tone conveyed of "shared responsibility" to increase enrollment.

- The largest geographic concentration of AI/ANs is the Navajo in the Southern part of Utah, but the Navajo Nation itself, and the health services available, are primarily located in Arizona.
- Four different IHS Area Offices share responsibilities for AI/AN health care in Utah.
- There is only one IHS direct service facility in Utah, in the Northeastern portion of the State, which is geographically inaccessible to the majority of the AI/AN population in Utah (the majority of AI/ANs are located in the Southern part of the State).
- The one 638 contract health facility in the State is not Tribally managed, but instead is managed by a Tribal organization, and all services provided are through Contract Health Service arrangements.
- While two other IHS health facilities are available, they are located outside of Utah in neighboring States, which means that AI/ANs in Utah who are enrolled in Utah Medicaid and SCHIP cannot receive reimbursed services from these facilities through Utah Medicaid and SCHIP.
- About one-half of the State's AI/AN population is located in urban areas, primarily Salt Lake City.

These characteristics have an impact on organized efforts to increase the enrollment of eligible AI/AN people into Medicaid, SCHIP, and Medicare. Because there is no major concentration of AI/ANs in any one location, and because the AI/AN population is widely dispersed across rural and frontier areas, targeted outreach, education, and enrollment assistance is difficult. In addition, the fact that there is only one IHS direct service facility, that serves only about one-fifth of the State's AI/AN population, means that the IHS is not in a position to conduct effective outreach and provide enrollment assistance to the majority of AI/AN people in Utah. The limited presence of the IHS in the State is further complicated by the overlapping IHS jurisdictions that are responsible for AI/ANs in Utah.

Incentives for aggressive efforts to assist AI/AN people to enroll in Medicaid and SCHIP are also reduced by the cross-border health care issues in Utah. Facilities in other States are not able to obtain reimbursement from Utah Medicaid or SCHIP, in most cases. As a result, there is no reason for them to seek to educate or assist AI/AN patients who may be eligible for these programs in Utah.

The Indian Walk-In Clinic in Salt Lake City does have strong incentives to ensure that people are enrolled in third-party programs since the Clinic receives only a small amount of IHS funding and is dependent on donations and Federal and State subsidies and grants for its operating budget. As a result, the Clinic makes concerted efforts to identify people who are eligible and to assist them in enrolling in Medicaid, SCHIP, and Utah's PCN program. It is noteworthy, however, that there is less interest in Medicare – primarily because the requirements for Medicare participation are substantial and the Community Health Center with which the Clinic contracts is not able to meet those requirements.

There appear to be low levels of attention to enrollment rates of this population by both the State and the IHS facility at Fort Duchesne. The State staff indicated that they did not think there was a serious under-enrollment issues, but did not have any data to support that perception. At the IHS facility, it was reported that, based on third-party coverage data in the Service Unit database, only about 6 or 7 percent were enrolled in Medicaid/PCN/SCHIP and that IHS staff believed that this was a substantial decline over enrollment a number of years ago. However, no reasons were put forth for this decline nor did there seem to be any coordinated effort to identify the reasons and reverse the observed trend.

# APPENDIX X.A: UTAH SITE VISIT CONTACT LIST

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# **Utah Indian Health Board**

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## **CHAPTER XI. WASHINGTON**

#### **BACKGROUND**

#### Overview

This Draft Case Study Report presents background information and findings from a three-day site visit to Washington State conducted from January 21-24 2003. The site visit team consisted of Sally Crelia (Site Coordinator) and Erika Melman of BearingPoint, and Rebecca Baca, project consultant, of Elder Voices. The team visited the Lummi Tribe of Indians in Bellingham, Washington, Yakama Indian Nation in Toppenish, Washington, and the Seattle Indian Health Board (SIHB) in Seattle, Washington, conducting interviews with individuals and groups in each location. The rationale for selecting the sites visited and description of the sites is provided in the following section.

An earlier version of this Case Study Report was reviewed by the Centers for Medicare & Medicaid Services (CMS) Project Officer and other CMS staff for accuracy and clarity. Subsequently, a Draft Case Study Report was sent to each of the Washington organizations that participated in the site visit, with a request that the draft be reviewed for accuracy and notification that comments and additions would be incorporated into the Case Study Report. Follow-up telephone contacts were made with all of these organizations. Comments and corrections were received from Lummi Indian Nation, Yakama IHS, the Washington Department of Social & Health Services, and the SIHB, and are incorporated into this report. Despite numerous follow-up contacts, no comments were received from Yakama Indian Nation.

The comments and recommendations contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or the feasibility of the recommendations. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of CMS, the Indian Health Service (IHS), or the State.

## Washington AI/AN Population and Location

The total landmass of Washington is 68,192 square miles, with a population of approximately six million.<sup>376</sup> Washington is a predominantly urban State, with 76 percent of the population living in urban areas and 24 percent in rural areas.<sup>377</sup> Currently, approximately 93,301 AI/ANs live in Washington (identified as AI/AN race alone on the 2000 U.S. Census), representing 1.6 percent of the State's total population. (If the definition of "AI/AN race alone or in combination with one or more other races" is used, the 2000 census reports 158,940 AI/ANs living in Washington, representing 2.7 percent of the State's total population.)<sup>378</sup>

<sup>&</sup>lt;sup>376</sup> http://www.encyclopedia.com/html/section/Washington\_FactsandFigures.asp, accesses May 29, 2003.

U.S. Census Bureau, State and County Quick Facts. http://factfinder.census.gov/servlet/BasicFactsTable?\_lang=en&\_vt\_name=DEC\_1990\_STF3\_DP2&\_geo\_id=04000US53, accessed May 29, 2003.

U.S. Census Bureau, State and County Quick Facts. http://factfinder.census.gov/servlet/BasicFactsTable?\_lang=en&\_vt\_name=DEC\_2000\_SF1\_U\_DP1&\_geo\_id=04000US53, accessed May 29, 2003.

Washington has 29 Federally Recognized Tribes: Chehalis Confederated Tribes, Confederated Tribes of the Colville Reservation, Cowlitz Tribe, Hoh Tribe, Jamestown S'Klallam Tribe, Kalispel Tribe, Lower Elwha Klallam Tribe, Lummi Nation, Makah Tribe, Muckleshoot Tribe, Nisqually Tribe, Nooksack Tribe, Port Gamble S'Klallam Tribe, Puyallup Tribe, Quileute Tribe, Quinault Nation, Samish Nation, Sauk-Suiattle Tribe, Shoalwater Bay Tribe, Skokomish Tribe, Snoqualmie Tribe, Spokane Tribe, Squaxin Island Tribe, Stillaguamish Tribe, Suquamish Tribe, Swinomish Tribe, the Tulalip Tribes, Upper Skagit Tribe, and Yakama Nation.

The educational status of AI/ANs in Washington is significantly lower than that of the State's overall population. According to 2000 census data, 22.6% of AI/ANs 25 years of age and over have not completed high school or a high school equivalency, compared to 11.9% for all races in Washington State. Poverty is also prevalent throughout Washington's AI/AN population. The per capita income for AI/ANs in Washington was \$13,622 in 1999, compared to \$22,973 for all races in the State. The AI/AN population in Washington is young compared to the State's all-races population. The median age for AI/ANs in Washington is 28.6 years; for all other races it is 35.3 years. The addition, a high percentage of AI/AN children in Washington State are uninsured. According to the 1998 Washington State Population Survey, 17.3 percent of all AI/AN children in the State were uninsured, representing 4.8 percent of all uninsured children in Washington. For comparison, 9.8% of Asian/Pacific Islander children were uninsured (8.3% of all uninsured children); 6.5% of African-American children were uninsured (3.5% of all uninsured children); 6.4% of White children were uninsured (65.2% of all uninsured children); and, 16.6% of Hispanic children were uninsured (18.2% of all uninsured children) in the State of Washington in 1998.

#### AI/AN Health Services In Washington

There are no IHS hospital facilities (either Tribally- or IHS- operated) in all of Washington State. As such, all inpatient/specialty services are provided through Contract Health Services and delivered by privately- or community-owned hospitals. There are, however, four IHS-directed health centers in the State: Colville PHS Indian Health Center in Nespelem; the Sophie Trettevick Indian Health Center in Neah Bay; the David C. Wynecoop Memorial Clinic in Wellpinit; and, the Yakama PHS Indian Health Center in Toppenish. There are also four IHS designated Tribally-operated health centers: Chehalis, Lummi, Puyallup, and Quinault. These health centers provide a wide range of clinical services and are open 40 hours each week.

There are several Tribally-operated health stations and preventive programs in Washington. Health stations provide a limited range of clinical services and usually operate less than 40 hours per week. Some of the health stations, however, provide a wide range of clinical services and operate a full 40 hours per week. Additionally, there are two urban clinics in

<sup>379</sup> 2000 U.S. Census Data Washington State, Tables: P37, P148C, P82, P13, P13C, and P157C

<sup>&</sup>lt;sup>380</sup> Health Policy Analysis Program (HPAP), University of Washington School of Public Health and Community Medicine, *Kids Health 2001 and the Washington State Campaign for Kids – an Evaluation of Outreach, Systems Change and Communications*, May 2002.

<sup>&</sup>lt;sup>381</sup> Indian Health Service Directory, July 2002.

<sup>382</sup> http://www.ihs.gov/FacilitiesServices/AreaOffices/Portland/, accessed 6/13/03

Washington: The SIHB in Seattle and the N.A.T.I.V.E. Health Project in Spokane. Both clinics are private, non-profit corporations.

## **Overview of Washington State Government**

The Washington State Governor's Office of Indian Affairs (GOIA) was initially established in 1969 to function as an Advisory Council (Council) to the Governor of Washington. After 10 years, the Council was abolished and replaced by a gubernatorially appointed Assistant for Indian Affairs. Renamed the Governor's Office of Indian Affairs, it has continued to serve as a liaison between State and Tribal governments in an advisory, resource, consultation, and educational capacity.

GOIA's goal is to recognize and affirm the government-to-government relationship and principles identified in Washington State's 1989 Centennial Accord and to assist the State in developing policies consistent with these principles. The principles of the Centennial Accord promote and enhance Tribal self-sufficiency, and the Accord mandates the GOIA to provide training to State agencies on information with which to educate employees and constituent groups about the requirement of the government-to-government relationship. 383

# **Washington State Medicaid Program**

The Washington State Medicaid Program is administered by the Medical Assistance Administration (MAA) of the Washington State Department of Social and Health Services (DSHS). The Medicaid program provides coverage for children, families, pregnant women, the disabled, and elderly persons.<sup>384</sup> Eligibility for the Washington Medicaid program is based on household income relative to the Federal Poverty Level (FPL). Specifically, the program covers children up to age 19 with income up to 200% of FPL; pregnant women with income up to 185% FPL; and families meeting Transitional Assistance for Needy Families (TANF)/State-funded Family Assistance (SFA) income and resource guidelines (100 percent of the Federal Poverty Level (FPL)).

Washington's Medicaid managed care plan is called Healthy Options. Healthy Options provides eligible families, children under 19, and pregnant women a complete medical benefit package with no premium or cost-sharing. Healthy Options members must choose a health plan (insurance company) from a list of plans that are contracted with the State. Healthy Options members must choose a primary care provider (PCP) from a list of doctors who contract with the health plan they choose, who coordinates all of their care (e.g., a physician, physician's assistant, or nurse practitioner).

In counties with only one managed care plan, clients may choose a fee-for-service option, which allows them to access care using their medical ID card (or coupon) from any provider who will accept this form of payment. Additionally, AI/ANs are offered a choice of Healthy Options, fee-for-service, or AI/AN or Tribal clinic services. Washington also currently has a small

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<sup>383</sup> http://www.goia.wa.gov/about/index.html, accessed May 22, 2003.

http://www.hipspokane.org/FieldGuide/glossary.htm, accessed May 5/22/03.

http://www.hipspokane.org/FieldGuide/healthyoptions.htm, accessed 6/12/03.

voluntary Primary Care Case Management (PCCM) program through which Tribal and IHS clinics serve as gatekeepers for those individuals in their service area who choose to enroll in the Healthy Options program.<sup>386</sup>

Persons can apply for Medicaid by obtaining and completing an application at a local office of the DSHS, a Community Service Office (CSO), or request that an application be mailed to them through a Statewide toll-free number. Applications can also be obtained online.<sup>387</sup> The application is a joint TANF/Food Stamp/Medicaid application. Although self-declaration of income was terminated effective April 1, 2003, there is no requirement for a face-to-face interview for eligibility determination and re-determination and applications can be mailed in. The State will attempt to verify earned income sources through on-line databases and other available information when possible. For cases when this verification is not possible, the State will request primary documentation, such as wage stubs. Medicaid eligibility is re-determined every 12 months (at the time of the site visit and interviews with the Tribes and DSHS in January of 2003, the determination period for families and children was every 12 months; the determination period has subsequently been shortened to every six months).

The Health Care Authority (HCA) of Washington also administers Basic Health, a State-funded managed care health insurance plan that provides State-subsidized health insurance coverage to low-income Washington residents who do not have access to employer-sponsored or other private insurance and whose incomes are too high to qualify for Medicaid. The program was intended to assure a health insurance option to low-income families and adults without children that would complement the Medicaid program, which funds mostly women and children. Those who are eligible may join Basic Health as individuals, or through a participating employer, home care agency, or financial sponsor group. See Children of adults enrolled in Basic Health who are under age 19 may be eligible for Basic Health Plus, a Medicaid program for children in low-income households who do not qualify for the regular Medicaid program. Eligibility is determined by the MAA based on the same eligibility criteria that is used for children in Medicaid (up to 200 percent of FPL).

#### **Washington SCHIP Program**

In May of 1999, the Governor of Washington authorized DSHS to implement Washington's State Children's Health Insurance Program. Washington's program, known as the Children's Health Insurance Program (CHIP), is a State and Federally-funded medical program for children under 19 years of age who are in a household earning between 200-250 percent of FPL. Washington CHIP, a separate child health program, is a Medicaid "look-alike" program. CHIP offers health care through both fee-for-service and managed care plans, with participating health plans the same as in the Medicaid Healthy Options program.

As with the Medicaid program, AI/ANs can choose from fee-for-service or a managed care plan, or can sign up with a PCCM clinic run by a Tribe or the IHS (Urban Indian health

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<sup>386</sup> http://cms.hhs.gov/medicaid/1915b/wa09fs.asp, accessed 6/12/03.

<sup>&</sup>lt;sup>387</sup> wws2.wa.gov/dshs/onlinecso/applying.asp, accessed 5/27/03.

<sup>&</sup>lt;sup>388</sup> The Kaiser Commission on Medicaid and the Uninsured , 5/13/02.

<sup>389</sup> http://www.basichealth.hca.wa.gov, accessed 6/12/03.

<sup>&</sup>lt;sup>390</sup> http://fortress.wa.gov/dshs/maa/CHIP/Program.html, accessed 5/22/03.

programs are not eligible to provide Contract Health assistance to its patients). AI/ANs may change health plans on a monthly basis.<sup>391</sup>

CHIP requires a \$10 monthly premium per child, up to a maximum of \$30 per family. 392 There are no premiums or copays for AI/AN children. 393 Children eligible for Medicaid or who have group health coverage are not eligible for CHIP. 394 The table below illustrates the qualifying income standards for Washington's CHIP and Medicaid programs.

Persons applying can use the short Children's Medical application form (DSHS form 14-380) or the Healthy Kids Now form (DSHS form 23-394x). Families can mail the application to their local Community Service Office and do not require an in-person interview. When applications are submitted, the Community Service Office will first review the case for Medicaid eligibility. Children ineligible for Medicaid and meeting other criteria will be enrolled in CHIP. 395 As of 2002, 4,086 persons were enrolled in CHIP. 396

#### **DESCRIPTION OF SITE VISIT**

#### Overview

Prior to conducting the site visit, the team contacted Spero Manson (Division of American Indian and Alaska Native Programs, University of Colorado Health Sciences Center), Technical Expert Panel (TEP) member; Ralph Forquera (SIHB), Rebecca Baca (Elder Voices), and Jo Ann Kauffman (Kauffman & Associates), Project Consultants; Ed Fox (Northwest Portland Area Indian Health Board); Nancy Goetschius (CMS Central Office) and Ernie Kimball (CMS Region X Office); and Doni Wilder, Lea Tom, and Cheryl Bittle (Portland IHS Area Office).

The team solicited advice on which communities the site visit team should visit in Washington, who initial key contacts might be, and which issues specific to the State should be addressed in the study. According to the Case Study Design Report approved by CMS, the team solicited input on one Tribal area with Tribally managed health facilities, one Tribal area with direct IHS facilities, and one urban area with an Urban Indian Health Center that delivers medical services. The team also stressed that travel distances were an important consideration in recommending sites.

The goal of the three-day site visit was to meet with approximately 10 to 12 key organizations/people per State. Also, as noted in the Case Study Design Report, if the urban area recommended was located in the State capital, the team would also try to schedule in-person

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<sup>391</sup> http://fortress.wa.gov/dshs/maa/CHIP/FAQs.htm, accessed 5/22/03.

<sup>&</sup>lt;sup>392</sup> Health Policy Analysis Program (HPAP), University of Washington School of Public Health and Community Medicine, *Kids Health 2001 and the Washington State Campaign for Kids – an Evaluation of Outreach, Systems Change and Communications*, May 2002.

<sup>&</sup>lt;sup>393</sup> http://www.hipspokane.org/FieldGuide/glossary.htm, accessed 5/22/03.

<sup>&</sup>lt;sup>394</sup> http://fortress.wa.gov/dshs/maa/CHIP/Program.html, accessed 5/22/03.

<sup>395</sup> http://fortress.wa.gov/dshs/maa/CHIP/FAQs.htm, accessed 5/22/03.

<sup>&</sup>lt;sup>396</sup> Washington State Hospital Association – Health Information Program, *Profile of Washington Health Plans*,

discussions with State Medicaid and SCHIP staff and IHS Area Office staff. Because the Portland IHS Area has no IHS hospital facilities (either Tribally-owned or IHS operated), the site visit team could only visit ambulatory clinics (all inpatient/specialty services in Washington are provided through Contract Health Services).

Advisors noted that there are substantial differences between Washington's eastern and western Tribes (as distinguished by east and west of the Cascade Mountains). Western Tribes are smaller; Eastern Tribes are larger and have less gaming (and therefore less income). In addition, most health facilities in the western side of the State are Tribally operated and participate in an administrative match program whereby the State reimburses a Tribal facility to conduct Medicaid outreach. Advisors suggested that the site visit team consider an east/west dichotomy in selecting the Tribes to visit to benefit from this diversity. They also noted that Tribes in Washington located nearer to urban Indian areas are less isolated and remote, and also more progressive in terms of public benefits enrollment and outreach. The more rural Tribes are more isolated and less likely to have large numbers of members enrolled in public benefits programs.

Based on the advice and information provided from the various sources, the team selected Lummi Nation, Yakama Indian Nation, and the SIHB for the site visits. This combination would enable the team to visit Tribes with substantial experience in outreach and enrollment, visit Tribes on both the east and west sides of the State, and visit an urban Indian clinic that conducts outreach and assists patients with accessing State services. The site visit team also arranged to meet with State Medicaid staff and Regional CMS staff while in Seattle.

Yakama is a large Tribe in the eastern part of the State, and is also the largest Tribe in Washington. Advisors stated that Yakama would be a good choice as it is still an IHS-operated facility and will likely remain so in the foreseeable future. Also, Yakama is adamant about the Federal Trust Responsibility of the government to provide health care through the IHS.

Advisors said that Lummi Nation would give the site visit team a valuable view of a Tribally-run clinic. It is a smaller Tribe than Yakama (about 4,000 members) in the western part of the State.

The SIHB is the largest and pre-eminent urban clinic both in Washington State and nationally. SIHB has significant experience with enrollment and managed care issues. SIHB is also involved in special activities with CMS, IHS, the Social Security Administration (SSA), and the National Indian Council On Aging (NICOA). SSA/CMS/IHS, under an interagency agreement, are working with NICOA and the SIHB to assist the AI/AN urban population in making informed healthcare choices by conducting an outreach and educational demonstration about CMS and SSA programs. Additionally, SIHB is participating in a demonstration project jointly funded by Washington State, CMS, and the SSA to train CHRs on outreach and enrollment issues.

The site visit team relied heavily on local Tribal and Urban Indian Health Center key contacts to determine which groups and individuals the team should speak with and at which places and times. The team sent a list of people the site visit team would like to interview to an identified key contact at each site. The list included Tribal leaders, Tribal Health Directors and

Tribal Health Board members, IHS Service Unit Directors, Contract Health Services Directors, Community Health Representatives/Community Health Aides, Title VI Directors/elder organization leaders, IHS hospital and clinic staff including alternative resource specialists, case managers, billing specialists, and patient benefits coordinators and counselors, urban Indian center and clinic staff, and other organizations that serve the AI/AN community (e.g., Area Agencies on Aging, out-stationed or County Medicaid/SCHIP eligibility workers, Indian Alcohol Treatment Centers, Indian Education Programs, and Tribal or County social services agencies). The individuals and organizations with whom the site visit team met in Washington or conducted follow-up telephone interviews are listed in Appendix XI.A.

# **Description of Lummi Nation**

The Lummi Reservation is seven miles northwest of Bellingham, Washington, and approximately 100 miles north of Seattle. The Lummi Nation signed the treaty of Point Elliott in 1855, ceding much of their native lands in western Washington to the United States government. In return, they received Reservation land that originally covered 15,000 acres. Today, approximately 12,000 acres remain under AI/AN control. A Tribal Council governs the Lummi Reservation. All Tribal members are members of the General Council, which meets at least once a year, at which time one-third of the Tribal Council is elected. There are 4000 enrolled members of Lummi Nation. 397

Lummi Nation operates an ambulatory direct health care center under a P.L. 93-638, Title III Self-Governance Compact with the IHS, the Lummi Indian Health Center. The Health Center offers general comprehensive medical and dental, mental health, substance abuse counseling, MCH/WIC, diabetes, family planning, community health outreach, and health education services. In FY 2001, 3,962<sup>398</sup> patients visited Lummi Indian Health Center for services, and in 2002, the Center experienced an estimated 35,000 ambulatory care visits. The Health Center employs doctors, dentists, public health nurses, pharmacists and pharmacy technicians, licensed practical nurses, certified mental health counselors, certified chemical dependency counselors, registered nurses, dental hygienists, nutritionists, and environmental health specialists. Psychiatrists and pediatric dentists are under contract to the Health Center as consultants. Primary care is provided to all eligible AI/ANs. In fact, some clients of the Health Center have alternate sources of care but prefer to receive services there rather than utilizing other sources of health care such as a private insurance or a managed care plan that does not contract with the Health Center as a PCCM. The Lummi Indian Health Center is accredited by the Joint Commission on the Accreditation of HealthCare Organizations (JCAHO) and bills third-party payers. The Tribe is also a State licensed Home Care Agency and provides personal and health care services to elders.

Lummi Nation is part of the Northwest Service Unit Health Board (a non-profit organization established in the early 1980s) that includes upper Skagit, Nooksack, and Swinomish. The Tribe's Contract Health Service Delivery Area (CHSDA) is Whatcom County.

<sup>397</sup> http://www.lummi-nsn.gov/, accessed 6/13/03.

<sup>398</sup> http://www.npaihb.org/profiles/Tribal\_profiles/interface.htm, accessed 6/13/03.

#### **Description of Yakama Nation**

The Yakama Reservation covers 1,573 square miles in the south-central Washington counties of Klickitat and Yakima. The city of Toppenish is located east of the Yakama Indian Nation's headquarters on the eastern part of the Reservation. The Yakama Nation Tribal Council governs the Yakama Reservation and its members. Self-government was re-established among Yakamas in 1935. Since the Indian Nation was made up of 14 bands and Tribes, each group selected a representative, forming the modern Tribal government. One-half of the Tribal Council members are elected every two years for four-year terms by members of the General Council, made up of all Yakamas 18 years or older.

The IHS operates an ambulatory health facility, the Yakama PHS Indian Health Center, located near Toppenish. The JCAHO-accredited facility houses Tribal and IHS-operated programs that offer a full range of ambulatory health and dental services. The Health Center has over 90,000 patient visits per year. General medical services are available, in addition to special services for well-child care, internal medicine, women's health care, and diabetes. The IHS employs physicians, dentists, physician's assistants, and the Tribe has contracted to manage some of the facility's auxiliary programs such as substance abuse, mental health, and elder meal programs. The health center bills third-party payers. Currently, approximately two-thirds of the clinic's budget is funded through Medicaid reimbursement. For FY 2001, IHS user population statistics for the Yakama IHS Service Unit included 16,839 Indian registrants, 11,866 active Indian registrants, and an estimated user population of 11,841.

In addition, the Tribe owns and operates the White Swan Health Clinic that is located in the rural community of White Swan, 20 miles west of Toppenish. White Swan offers limited primary care, and operates an ambulance service using EMTs and First Responders. Itinerant health and social services are offered through the maternal and child health, nutrition, WIC, CHR, and alcoholism programs. The Tribe also operates a satellite Maternal and Child Health center in the Apas Goudy Housing Project in Wapato. The Tribe's Contract Health Service Delivery Area (CHSDA) is Klickitat, Lewis, Skamania, and Yakima Counties.

## **Description of The Seattle Indian Health Board**

The SIHB is a non-profit, multi-service community health center chartered in 1970 to serve the healthcare needs of AI/ANs living in the greater Seattle/King County region. The mission of SIHB is to assist AI/ANs in the achievement of the highest possible physical, mental, emotional, social, and spiritual well-being through the provision of culturally appropriate services, and to advocate for the needs of all AI/AN people. A 15-member Board of Directors, the majority of whom are of AI/AN heritage, governs the agency. Staff includes an executive director, associate director, medical director, operations coordinator, and division managers.

Direct care services at SIHB are provided on a sliding fee basis. SIHB accepts many public and private insurance plans. Additional funding is received from public and private

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<sup>&</sup>lt;sup>399</sup> Interview with Yakama PHS Indian Health Center staff, 8/14/03.

<sup>&</sup>lt;sup>400</sup> Interview with Yakama PHS Indian Health Center staff, 1/22/03.

http://www.ihs.gov/NonMedicalPrograms/IHS\_Stats/files/Userpop01.pdf, accessed 6/13/03.

sources including Federal, State, and local government agencies. The agency is a Federally Qualified Health Center (FQHC) for Medicaid and Medicare services. Some programs have restricted enrollment based on grant or contract provisions. SIHB also contracts with the IHS under Title V of the Indian Health Care Improvement Act (PL 94-437).

All SIHB programs are State-licensed and nationally accredited by JCAHO. Direct care providers are State-licensed; many are also board-certified in their respective fields. SIHB provides medical (primary and preventive), dental, mental health, substance abuse, traditional native health, pharmacy, nutrition and WIC, community outreach, and domestic violence services at the Leschi outpatient clinic and at the Thunderbird Treatment Center (residential drug and alcohol treatment). The medical services staff consist of family practice and pediatric physicians with hospital privileges, advanced registered nurse practitioners, registered nurses, licensed practical nurses, physician assistants, medical assistants, pharmacists, nutritionists and laboratory technicians. SIHB's Traditional Health Liaison works with all service departments of SIHB to assess, consult, refer, arrange and/or provide traditional healing services.

SIHB also houses the Urban Indian Health Institute (UIHI), a national research and epidemiology center for urban Indians. The UIHI provides centralized nationwide management of health surveillance, research, and policy considerations regarding the health status deficiencies affecting urban AI/ANs. 402

Finally, SIHB sponsors the Family Practice Residency Program, a training experience for those considering careers in a non-profit health care setting with a special focus on Indian health. Established in 1994, the SIHB Family Practice Residency Program was created to increase the number of family physicians skilled in caring for low-income Americans with a special focus on AI/ANs. The residency is part of the University of Washington's Regional Family Practice Network. Attending physicians are board certified and on clinical staff at the University of Washington School of Medicine. Instruction is augmented with additional SIHB health care professionals and exposure to traditional Indian medicine is an integral part of the training curriculum. 403

Prescriptions from SIHB providers can be filled at an on-site pharmacy (prescriptions are subsidized on a sliding-scale fee basis if filled at SIHB) or patients may fill prescriptions at an outside pharmacy. Given the volume of prescriptions and the cost of maintaining a reasonably varied formulary, SIHB is exploring the idea of charging a co-payment for prescriptions filled at its in-house pharmacy.

## **Description of Other Organizations Interviewed**

The site visit team interviewed representatives from Washington State's "Covering Kids" pilot program. In 1997, The Robert Wood Johnson Foundation established *Covering Kids: A National Health Access Initiative for Low-Income, Uninsured Children* to help States and local communities increase the number of eligible children who benefit from health insurance coverage programs. The \$47 million initiative eventually funded projects in 50 States and the

<sup>402</sup> http://www.uihi.org/background.asp, accessed 7/14/03.

http://www.sihb.org/fpr index.htm, accessed 7/14/03.

District of Columbia, including pilot communities. Washington State conducted a pilot project under Covering Kids targeted at the uninsured children in the State, three quarters of whom were thought to be eligible for State-subsidized health coverage. The project's goal sought to reduce the number of uninsured children by half over its three-year duration. The project deployed new outreach efforts to provide information and enrollment assistance through community organizations, including schools and community centers. It also sought to simplify the application process further by linking Medicaid application to applications that families already complete for free and reduced-price lunch programs and other subsidized food benefits. The Washington Covering Kids project had a component aimed at AI/AN children, 11.6 percent of whom were estimated to be uninsured at the beginning of the project (double the collective uninsured rate for children of other races).

# FINDINGS: WASHINGTON MEDICAID AGENCY<sup>406</sup>

## Washington Department of Social and Health Services

#### Overview

The site visit team interviewed Rick Arnold, the AI/AN liaison from the Division of Policy and Analysis of the MAA of DSHS. Mr. Arnold serves as the main point of contact with Tribal health systems in the State. In general, DSHS believes there are problems with underenrollment in Medicare, Medicaid and SCHIP, but that limited data makes it very difficult to estimate the magnitude of the problem. While the extent of under-enrollment is unknown, information on actual enrollment suggests that 20%-40% of revenues for health clinics in Washington come from third-party billing. This statistic demonstrates that CMS and the State government are essential sources of revenue for many Indian health centers in Washington.

DSHS commented on Tribes' reports that the State and Federal governments have failed to take part in meaningful Tribal consultation process before making policy changes that affect AI/ANs. Staff said that Tribes have not taken steps to define this process. DSHS commented that Tribes need to come to consensus amongst themselves as to who represents their interests Statewide, regionally, and nationally, and that the responsibility lies among them to build consensus around the issues that affect them.

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<sup>404</sup> http://www.coveringkids.org/projects/State.php3?StateID=WA, accessed 6/12/03.

Interview with Washington Covering Kids Pilot Project staff, 2001.

Office, due to his high level of coordination with AI/AN activities in Washington. Mr. Kimball echoed many of the State's comments. Additional comments made specifically by CMS are as follows: "There is a need for more culturally-specific information about the programs targeted towards AI/ANs, explaining the programs' benefits and enrollment process. This should be accompanied by more consistent and on-going training, that is also culturally specific for AI/ANs, targeting key Tribal workers such as CHRs, case managers, outreach workers, and resource advocates. While information on these programs currently exists, this information is not relevant or easy to understand or use by the AI/AN population. Also, while the State does provide training on eligibility and enrollment, this training could be more targeted to the specific needs of the AI/AN population. Training should be on-going and recurrent." The CMS representative also suggested that CMS headquarters could provide CMS regional staff with additional technical assistance and training to build their capacity to develop more regional level training strategies targeting AI/ANs. Building the capacity of these regional staff to develop training programs, create training modules and provide this training to AI/ANs would enable these staff to provide more support and assistance to AI/ANs with respect to increasing enrollment in the programs.

DSHS staff responded to the fact that Tribes have reported that the redetermination process causes many people to become disenrolled from Medicaid. Staff noted that getting on and staying on the program is easier than it has been in the past since Washington eliminated the face-to-face interview for eligibility determination and redetermination. In addition, Medicaid eligibility is re-determined only once every 12 months (as noted earlier in the report, at the time of the interview with DSHS, the determination period for families and children was once every 12 months; the determination period has subsequently been shortened to once every six months).

DSHS also responded to the idea that Tribal and IHS clinics would like to see more outstationed eligibility workers. DSHS stated that the reason some out-stationed positions have been eliminated is due to the light caseload of many of these caseworkers. It is not cost-efficient for DSHS to pay for an out-stationed eligibility worker who may process one or two applications a day. DSHS did indicate, however, that the agency would be responsive to coordinating the outstationing of more DSHS workers if Tribes would be willing to cover the salary of these workers.

In addition, DSHS commented on the opinion expressed by some interviewees that Medicaid managed care can serve as a barrier to enrollment for AI/ANs in Medicaid. Interviewees stated that unless AI/ANs actively opt out of managed care, they are automatically enrolled in a managed care health plan. At the time of enrollment, the State presents them with several managed care plans as options and most do not realize they can receive their Medicaid services through an IHS, Tribal, or urban Indian facility. DSHS countered that there are several mechanisms in place to ensure that AI/ANs are offered the opportunity to enroll in either an IHS or Tribal facility as a PCCM, or to enroll in fee-for-service. The Medicaid application includes a question about applicants' race. If applicants check off the box affirming that they are AI/AN. they are automatically exempted from managed care and assigned to the closest IHS or Tribal facility as a PCCM. If applicants are located in an area without any IHS or Tribal facilities (determined by the zipcode listed by the applicants in the home address portion of the application), they will still be exempted from managed care and automatically enrolled in feefor-service. In this case, AI/ANs have several options. They may choose any fee-for-service physician accepting Medicaid patients, they may utilize an urban Indian clinic to receive services, or they may travel to an IHS or Tribal facility to receive care. In all of these cases, the provider will be able to bill for services since these individuals are in fee-for-service.

DSHS also commented on interviewees' comments that even though these safeguards exist to automatically exempt AI/ANs from managed care, many AI/ANs fall through the cracks. Interviewees stated that many AI/ANs fail to identify themselves as AI/AN on the application for a variety of reasons; the question is optional and they do not realize that answering the question will impact their application; they believe that they will be treated in a negative manner by the Medicaid office if they identify themselves as AI/AN; or, they simply do not want to reveal personal information to the State. Interviewees also stated that many AI/ANs move frequently between their Reservation and more urban areas to seek work. Therefore, the address they record on their application may not be reflect where they are actually residing for large portions of the year. In addition, AI/ANs may have no or unreliable mail service where they are residing so the address they report may be that of a friend or relative. As such, DSHS's process of exempting

applicants from managed care and automatically enrolling them in fee-for-service based on their zipcode may not be a viable method, even if they are assigned an IHS or Tribal facility as a PCCM. For instance, an AI/AN who becomes a managed care enrollee because they list an address near a Tribal facility but who spends half the year on a Reservation and half their time in an urban area presents a problem for urban clinics, as the clinic would not be able to bill for services provided to this individual since they are a managed care enrollee.

Finally, DSHS responded to the fact that some Tribes in Washington feel that there is a lack of standardization in terms of definitions of services and interpretation of Medicaid rules. DSHS agreed that a uniform interpretation of Medicaid rules is necessary, including defining the range of services allowable under the all-inclusive rate, and clarifying the definition of an encounter. DSHS expressed that it is willing to work with Indian health boards in Washington to develop processes of Tribal consultation and definitions of Medicaid rules. DSHS, however, said that a documentation of needs and proposals for fulfilling these needs has to come from the Tribes initially so that the State knows what these needs are. The State is often faced with hearing two opposing arguments from Tribes. On one hand, some Tribes do not believe that Medicaid is part of the Federal Trust Responsibility and take the stance that funds should come through the IHS. On the other hand, in order to keep afloat financially, these same Tribes are looking for ways to interpret Medicaid regulations so that they can bill for Tribal members with Medicaid coverage (even though the Tribal council may not advocate enrollment and public benefits outreach).

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Staff reported that while under-enrollment in Medicaid, SCHIP, and Medicare exists, it is difficult to quantify the extent of this problem due to a lack of data. It might be possible to obtain rough estimates of under-enrollment figures from various sources (e.g., Tribal data and income data), but no reliable numbers are available. This lack of data itself is a barrier to enrollment. If the pockets of under-enrollment are not identifiable, neither the State nor the Federal government can formulate outreach strategies to target these pockets.

#### Barriers to Initial Enrollment

DSHS staff noted important policy issues that they believe impede AI/AN enrollment in Medicaid and SCHIP.

• DSHS staff discussed how the increase in Tribal management of health facilities has created conflicting signals for Tribes with respect to enrollment in public health insurance programs. When health facilities were all managed by the IHS, Tribes could point to the Federal government as the "bad guy" if there were problems. With Tribal self-governance, however, Tribes are sometimes faced with being even more restrictive (such as aggressively screening patients for their program eligibility) than either the State or Federal governments in order to increase their revenue and maximize the use of their fixed IHS funds. Some Tribes are willing to take on this role. Others, however, are not willing to take on the role of the "bad guy," and would rather not encourage enrollment in public health insurance programs to avoid than be viewed negatively by Tribal members.

- Staff discussed the fact that the more a Tribal council supports third-party billing, the more vigilant are clinic staff about patient screening and enrollment. Some Tribes, on the other hand, are less exacting in requiring screening due to a variety of reasons: lack of infrastructure to bill to third parties, lack of knowledge about the benefits of billing to third parties, or philosophical opposition to receiving money through a program intended for the overall population (i.e., the interviewees said that some Tribes would rather have less health services available to them with only their IHS funds rather than accept money outside of the IHS system for more diverse and comprehensive services).
- The extent of interest Tribal members exhibit for enrolling in programs and the extent that Tribal leadership encourages and supports enrollment can be based on the location of the Tribe. Staff commented that Tribes in rural areas, in general, are more traditional than urban Tribes and less likely to support enrolling in and billing for public health insurance programs. There is also less incentive for members of rural Tribes to enroll because a lack of transportation makes it difficult to access providers from remote areas. According to the interviewees, Tribes nearer to urban areas are more familiar with the benefits of enrolling in public health insurance programs, such as gaining access to a choice of nearby providers, and thus more likely to see the advantage in enrolling than their rural counterparts.
- The shrinking State Medicaid budget is also a barrier to enrollment for AI/ANs. The State's Medicaid budget crisis provides a disincentive for the State to conduct public benefits outreach. On the one hand, the DSHS has curtailed marketing and outreach for Medicaid programs. At the same time, Tribes are requesting out-stationed eligibility workers in order to increase enrollment. This situation leaves the DSHS in a precarious position. The agency would face criticism if it were to fund eligibility workers for Tribes at the same time that it is eliminating outreach to the rest of the population.

## Barriers to Maintaining Enrollment

The interviewee did not cite any barriers to maintaining enrollment in Medicaid or SCHIP

<u>Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings</u>
Programs<sup>407</sup>

• The shrinking State Medicaid budget also has negative implications for marketing and outreach with respect to the Medicare Savings Programs.

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<sup>&</sup>lt;sup>407</sup> The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

## Strategies to Increase Enrollment in Medicaid, SCHIP, and the Medicare Savings Programs

- **Designated State AI/AN Liaison.** DSHS suggested that a key strategy to increasing enrollment in these programs would be to have an AI/AN representative employed by the State who is trained in eligibility and enrollment issues, such as a designated Community Service Office (CSO) worker, out-stationed at AI/AN sites (such as on Reservations and at urban clinics). Having a designated liaison from the State work twice a week at AI/AN sites would help AI/ANs overcome the lack of transportation to and perceived discrimination at CSO offices. Some regions of the State already have AI/AN liaisons from local CSO offices. Providing more would also ensure that more AI/ANs are made aware of the programs and their benefits and would help to streamline the process of enrollment and redetermination.
- Increased Responsibility for Tribes. Finally, DSHS suggested that the Tribes in Washington State should take on more responsibility in developing systems to increase enrollment in these programs. Tribes should be more assertive in assuring that they are receiving and taking advantage of all of the government funds that are available to them. Some examples of how Tribes could take on more responsibility include developing their own training programs to ensure key staff are knowledgeable about the eligibility and enrollment issues of the programs. They could also develop more comprehensive and consolidated systems of identifying, screening, and assisting eligible persons to enroll. Another suggestion was for Tribes to take advantage of lessons learned or best practices from other Tribes that have been successful in increasing enrollment. For example, some Tribes have contracted with the State to get reimbursed for providing additional sources of transportation to AI/ANs to get to and from the CSOs by hiring medical transportation brokers.

#### Other Issues

DSHS commented on the fact that some Tribes are not satisfied with the encounter rate they receive for Medicaid services. According to DSHS, the current IHS facility encounter rate, \$197, can be more than the fee-for-service encounter rate, depending on the costs associated with the services performed. As such, DSHS believes that AI/AN clinics are already receiving more than other providers in certain cases. 408

#### FINDINGS: LUMMI INDIAN NATION

#### Overview

During our site visit to Lummi Reservation, the site visit team discussed program enrollment barriers and solicited strategies to increase enrollment in Medicaid, SCHIP, and

<sup>&</sup>lt;sup>408</sup> Representatives from Lummi Indian Nation provided the following comment in response to this Statement: "The tribes disagree with this Statement. First and foremost, the encounter rate cannot be compared directly with the fee-for-service for a like medical visit, as the State does not know in detail the auxiliary services portion of the visit, ie., laboratory and radiology. The encounter rate may, for some services, be four times the allowable physician fee. Also, two cost studies completed by tribes that suggest that the IHS facility encounter rate does not reimburse fully the direct and indirect cost experienced by tribes for providing the services. Again, we disagree with the State's Statement."

Medicare with three levels of staff at the Lummi Indian Health Center: day-to-day "line" staff, clinic administrators, and health policy planners. The team met with the Reservation's Tribal Health Planner and the Life Center Director of the Tribal Health and Human Services Division. In addition, the site visit team met with the business office manager, a benefits coordinator, and an office assistant from Lummi Indian Health Center.

The interviewees communicated that Lummi is a very traditional Tribe, and that while the clinic does bill third parties to a limited extent, the Tribal council has not always supported the requirement that Lummi members must apply for Medicaid. The Council's official position is that all health care dollars (including Medicaid and Medicare) should come through the IHS (i.e., if a person is eligible for Medicaid or Medicare, the funds should go through the IHS and not a State Medicaid or Federal Medicare office). Even if this were possible, the Council supports opting out of public programs entirely if it could be guaranteed that the IHS would be funded at 100 percent of the health care needs of AI/ANs. Staff at the clinic stressed that they, too, support this idea.

While clinic staff may not philosophically support public benefits enrollment, they do support it in the practical sense that third party billing permits them a more flexible budget and the ability to offer more comprehensive health services. They said they are faced with barriers within the Tribal leadership, however, to implementing an aggressive screening process for third party billing. First, since Lummi is a very traditional Tribe, patients would be resentful if a screening process were implemented for initial registration. Currently, patients are only screened once they are in an in-patient situation and the clinic receives notification from a hospital for payment. Alternatively, if the clinic knows that the patient will require in-patient services in excess of \$2,000, clinic staff can contact the hospital beforehand to initiate the application process. Another way that a patient can get into the public benefits system is when the patient is routed by clinic staff to the Maternity and Child Health Center for maternity care.

Second, the clinic staff would have to get more Tribal council support before implementing methods to increase enrollment. Even though the clinic staff may want to bill to third parties, they have the responsibility to educate the Tribal Council on the benefits of third-party billing. As with any governing body, there is a frequent turnover in elected Tribal leadership. As such, clinic staff are faced with re-educating the Tribal council repeatedly on the concept and benefits of third party billing. The Health Commission is the governing body of the clinic but the Council appoints the Commission members and as such, the same issues that exist with the Council exist with the Commission. The clinic staff must work on all levels (individual patient, Health Commission, and Tribal Council) to get support for third party billing.

Interviewees also noted that if such support became a reality, education materials would be needed for everyone, not just patients, as the support for third party billing would represent a shift in philosophy and a resolution to the question of whether the Tribe receiving money through public benefits programs is part of the Federal Trust Responsibility, or whether the fact that AI/ANs must seek out enrollment in these programs is due to the fact that the Federal Trust Responsibility of providing services through IHS is not being carried out. Clinic staff believe that eventually the clinic will begin to more aggressively bill to public insurance programs out of fiscal necessity, but that this is not necessarily what they want to do philosophically.

In terms of current enrollment, interviewees estimated that there is a sizeable number of children who are eligible but not enrolled in CHIP and Medicaid. While Tribal health staff did not know the actual number of under-enrollment among Tribal members, they did note that 40 percent of elders are below the poverty level and 47 percent of children are living below the poverty level. They estimated that even lower percentages of each population are enrolled in public insurance programs (as of February 2003, 23.2 percent of their active users enrolled in Medicaid). They noted that very few Tribal members are enrolled in CHIP because Medicaid covers children ages 1-19 up to 200 percent of FPL, a higher threshold than some other States. CHIP covers children between 200-250 percent of FPL. Staff believe that, based on their poverty rates and in comparison with other Tribes who are very aggressive in enrolling their members in Medicaid, that their rate should be between 45-55 percent.

## Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

Interviewees most frequently reported the following barriers to initial AI/AN enrollment in Medicaid and CHIP:

- Securing transportation to the County Medicaid office, which is 10 miles away, presents a challenge for many Tribal members. Some AI/ANs are not aware that there are alternate methods to applying for the programs other than in person at a local CSO office. This lack of awareness presents several problems. Along with the difficulties for many AI/ANs in securing reliable transportation to a CSO office, some AI/ANs are reluctant to visit a CSO office due to issues of privacy and pride and a hesitancy to disclose personal information to strangers. Additionally, interviewees said that many AI/ANs do not want to provide confidential information to government agencies due to mistrust of government agencies and services.
- Patient resource staff believe that the application for Medicaid and CHIP is not user-friendly. Much documentation is required and patients generally do not have the required documentation with them at the time of a clinic visit. Follow-up with those who do not have the proper documentation to complete an application at the time of a clinic visit is difficult via mail and phone due to the fact that many AI/ANs move frequently and many do not have phones. Also, for many AI/ANs, the different medical assistance programs for the needy such as Medicaid, CHIP, and Basic Health, are so overwhelming that they do not want to start or continue with the application. Also adding to the confusion is that many AI/ANs do not understand that Healthy Options is the same program as Medicaid. They become so confused about the application process that they do not want to enroll in any programs.
- While there are AI/ANs who are aware of and eligible for the programs, many still choose not to enroll for a variety of reasons. Much of the Tribal population still feel very strongly that the Federal government promised them health care and that they should not have to enroll in programs intended for the non-AI/AN population to receive that care. Interviewees also said that many potential AI/AN beneficiaries do not understand that

Indian health care funded through IHS is discretionary funding by Congress and is not an entitlement program (although AI/ANs are entitled to care at any IHS facility, there is no guarantee about the extent of services that the facilities will provide). That is, while Indian health care is an entitlement, the Indian health care budget is discretionary. Medicaid, on the other hand, is an entitlement program funded on an entitlement basis. Anyone that is eligible to receive Medicaid receives the same health benefits package as do other Medicaid beneficiaries in the State. The lack of understanding about the differences in the funding mechanisms of these two types of programs is a particular issue with elders.

- Staff noted that Lummi Health Clinic is prohibited from serving as a PCCM for many Medicaid managed care plans. Staff feel that this is a reason that more AI/ANs do not enroll in programs. Many AI/ANs think that if they sign up for Medicaid they will no longer be able to receive services at all from the Lummi clinic. (While they could still receive services at the Lummi clinic, Lummi could not bill for these services).
- Another barrier to enrollment is the lack of understanding surrounding program denials. Many AI/ANs do not realize that a denial can be appealed. In fact, sometimes a denial from one program is necessary to pursue enrollment in another. For instance, families that are screened for Medicaid and found ineligible due to income higher than the Medicaid threshold can still pursue CHIP for the children in the family. Furthermore, many AI/ANs think a denial means that they are not eligible or qualified, even if the denial is due to a lack of paperwork. Also, many AI/ANs do not realize that a change in economic/medical conditions can make someone eligible who previously was not. Denials are especially difficult for clinic staff to address, because many AI/ANs do not even question a denial letter. If those who received denial letters approached patient resource staff for help, staff could guide the applicant through the process of applying for another medical assistance program or could point them in the direction of another agency so that they may pursue eligibility via another program, such as SSI or SSDI. For those who wish to appeal denials, however, the clinic does not have the capacity to provide legal assistance.
- Some AI/ANs are reluctant to enroll in a public benefits program because they fear they may have to pay back funds received once they make enough money and are no longer eligible. Because of this fear of recovery, many AI/ANs are reluctant to enroll even if they have acute health care needs.
- Some applicants will stop completing a Medicaid application when they see the question that requests naming the father of a child. The State requires this information so they can pursue child support. Interviewees reported that some CSO workers, if the applicant has gone into a local CSO office to apply, will often pressure the applicant to provide such information. According to interviewees, TANF regulations in Washington are such that women who fail to cooperate with States in paternity issues cannot be covered by Medicaid (although her children can be covered).
- Although the clinic completes the paperwork necessary to adhere to all the regulations of the administrative match program, the extra paperwork that the clinic has to complete to

receive the administrative fee often does not make it worth the staff's time. The intent of the administrative match programs was to create an incentive for the Tribe to get more people on programs but the "line" staff, who are responsible for the paperwork, find it too cumbersome a process.

## Barriers to Maintaining Enrollment

Interviewees did not cite any barriers to maintaining enrollment in Medicaid or CHIP.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

According to those interviewed, many elderly Tribal members do not have Medicare Part A because they were self-employed and do not qualify because of a lack of 40 quarters' contribution

Of those eligible for the Medicare Savings Programs, interviewees stated that they are generally either unaware of the programs or are too proud to enroll because of the social stigma associated with welfare. Interviewees estimated that there is a significant problem with underenrollment in Medicare Part B and the Medicare Savings Programs, and that there is moderate under-enrollment in Medicare Part A.

The interviewees reported the following reasons for under-enrollment in Medicare Part A and B and the Medicare Savings Programs:

- Staff noted that the welfare stigma associated with Medicaid coverage makes it a "hard-sell" to elders and keeps many eligible elders from enrolling in the Medicare Savings Programs. In addition, the cost-sharing requirement of some of the Medicare Savings Programs (e.g., SLMB) is a deterrent for other elders because even if their Medicare Part B premiums were paid, they still do not feel they could afford Part B coinsurance and deductible amounts.
- While many elderly AI/ANs are aware of the Medicare program, some still choose not to utilize Part A or enroll in Part B for a variety of reasons. The Federal Trust Responsibility is particularly important with respect to understanding why some elder AI/ANs do not want to enroll. While a larger percentage of younger Indians have accepted the idea of public health insurance programs, many elders feel very strongly that the Federal government promised them health care and that they should not have to enroll in programs intended for the non-AI/AN population to receive that care. In addition, many elder AI/ANs also have a general feeling of mistrust towards the government because of the historical tension between AI/AN governments and the U.S. government.
- Most AI/ANs at Lummi are not aware of the Medicare Savings Programs and do not apply for QMB/SLMB coverage. If they are aware, or are made aware by outreach workers, benefits coordinators, or CSO caseworkers, barriers such as not knowing where to go for help with paperwork deters people from enrolling.

• Staff mentioned that they used to communicate by letter to the head of DHHS or directly to the U.S. President. Now, they communicate with the regional CMS office. However, they feel that the regional offices' true clients are the States, and that Tribes need the ear of an entity more senior in the Federal government that possesses the authority to actually make policy changes with respect to AI/AN enrollment in public benefits programs.

Interviewees discussed their precarious position with respect to the Federal Trust Responsibility and mentioned several options that they believe would ease any vacillation about whether or not to endorse enrolling in public benefits programs. One option is to resolve to work within the existing funding system for AI/AN health care (a combination of IHS base funding and reimbursement through public benefits programs). Another option is to work for national changes in the funding system such that the IHS is funded at 100 percent of their needs, thus eliminating the need for enrolling in public health insurance programs to obtain additional funding. Currently, staff cannot make that decision because in order to keep the clinic afloat financially, they need to bill public health insurance programs although many clinic and Tribal staff are philosophically opposed to AI/AN involvement in these programs. Interviewees suggested that the onus is on CMS to formalize the relationship of public health insurance programs to the Federal Trust Responsibility.

That is, interviewees feel that the Federal government should decide whether or not AI/AN participation in public benefits programs are an official part of the Federal government's fulfillment of the Federal Trust Responsibility. As it currently stands, staff feel that they are in a contradictory position. They want to advocate for AI/AN rights within public benefits programs in order to ensure that AI/ANs get the medical care they need. Staff also bill for programs because they need the funding, since the Indian health care system, composed of three parts: The Indian Health Service (I); Tribal-operated health facilities (T); and Urban Indian health facilities, also known as I/T/U, is not funded at its full need. But, staff also do not philosophically believe that public benefits programs are part of the trust responsibility. So, on one hand staff are utilizing and advocating for AI/AN rights within public health insurance programs. On the other hand, they are advocating for changing the funding system because they do not want AI/ANs to have to enroll in these programs to receive care and for the clinic to receive additional funding. If the government officially makes these programs part of that trust responsibility, then AI/ANs can concentrate on advocating for AI/AN rights within public benefits programs. If the government's official position is that they are not part of the trust responsibility, advocates can concentrate on fighting for 100 percent funding of the I/T/U system.

Another option mentioned by interviewees is for the Federal government to move Medicaid, SCHIP, and Medicare monies into the I/T/U "pot." This would fund the Indian health care delivery system at its actual need on an entitlement funding basis, fulfilling the trust responsibility and eliminating the need for AI/ANs to advocate for their rights within a system meant for the overall public. Whatever the outcome, interviewees stressed that long-term planning and policy changes are necessary.

Finally, staff expressed frustration at the mixed messages delivered by the social welfare system. The Federal and State social welfare systems encourage individuals to become increasingly self-sufficient and self-reliant as they transition from unemployment or low-income jobs to better-paying jobs. As this happens, many individuals are no longer eligible for programs

in which they may be enrolled, such as Medicaid. However, they also may not have access to health insurance from any other source. If that is the case, individuals seeking services at the Health Center can still receive care through Contract Health Services. However, because IHS is the payor of last resort, these individuals may have to present a denial from other programs in order to access services via Contract Health. While this is financially necessary for the Health Center, interviewees felt that the process that AI/ANs have to go through to get a denial, such as disclosing private financial information, penalizes and demoralizes them for becoming financially independent.

## Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

Interviewed staff members had several suggestions for increasing enrollment in the three programs:

- Educate Tribal Members about program benefits. Staff reported that in order to "sell" the programs to potential beneficiaries, it is important to promote the benefits of enrolling in programs. For instance, an effective message might stress that individuals enrolled in Medicaid have a choice of receiving services at an IHS or Tribal facility or from another provider. This choice would enable a beneficiary to get a second opinion if needed or desired.
- Standardardize Medicaid benefits. Interviewees suggested that a national Medicaid benefit package would help them with cross-State-border issues and ensure that the Federal Trust Responsibility is consistent from State to State. Clinic staff expressed frustration that the Federal Trust Responsibility of the government changes across States based on how a particular State has chosen to administer its Medicaid program. In their opinion, the Federal Trust Responsibility should apply equally to AI/ANs in any State, and a standardized Medicaid benefits package would help to enforce this idea. Interviewees suggested that an alternative to a national Medicaid package would be for CMS to contract with every State for a separate AI/AN Medicaid program. For instance, in Washington there would be a DSHS for the non-AI/AN population, and a DSHS for AI/ANs.
- Standard and diverse definitions of Auxiliary Medical Programs. Clinic staff remarked that the adoption of a standard and more diverse definition for complementary services that can be billed for under Medicaid and CHIP, such as cultural medicine, would help the clinic develop programs. Currently, Tribes are reluctant to spend money to develop such auxiliary programs because there are no standard definitions of the services for which the clinic can bill.
- **Definition of terms.** Staff said that standardization of the terms "Tribal consultation" and "AI/AN liaisons" across States and the Federal government would be helpful. Currently, Tribes negotiate individually and in a unique manner with State and Federal governments and with liaisons within State and Federal departments. Interviewees felt that there should be a standard definition of how States and the Federal government should consult with Tribes, as well as a standard definition of the role and authority of State and Federal liaisons. These definitions would clarify what level of government a Tribe should

communicate with for various requests, and would help Tribes determine the level of authority a State or Federal AI/AN liaison possesses. During the site visit, Lummi staff gave the BearingPoint site visit team a policy paper on Tribal consultation that they had prepared. This paper appears as Appendix XI.B as an example of how Tribes can help clarify the concept of Tribal consultation and give direction to the Federal government on how to carry out the process of Tribal consultation.

- Education about public benefits programs. Staff noted than increased education about public benefits programs would raise awareness of the programs. This would increase interest in enrolling, as well as educate people about what the application process will entail (such as the amount of required paperwork and the type of information they will have to disclose) so that they can make an informed decision about whether or not to enroll. Interviewees said that income sharing is a barrier to enrollment for Tribal members at all ends of the income spectrum, as the sharing process itself takes away dignity from potential beneficiaries. If applicants were informed ahead of time of the information they would have to reveal, as well as which information would be kept confidential and which could possibly be made public, this knowledge would help AI/ANs not only make a more informed choice but to increasingly trust the State and Federal governments. As trust of the State and Federal governments on the part of AI/ANs increases, the more likely they will be to disclose the personal information necessary to complete applications for public benefits programs.
- Few but more comprehensive programs. Staff would like to see a smaller number of more comprehensive State medical assistance programs, and a simplified application form. They stated that there are too many Medicaid eligibility categories. This creates confusion among staff and potential beneficiaries about which medical assistance programs might be appropriate for the applicant. Also, the different medical assistance programs require a lengthy application form. Staff believe that if there were fewer and less complicated eligibility categories, this would give them a stronger ability to identify if an applicant might be eligible for medical assistance and help with the application process.
- Education materials. Clinic staff reported they need help creating education materials that effectively educate Tribal members to assist them in making an informed decision to apply or not to apply for public benefits programs. In general, potential beneficiaries do not understand how Federal and State funding mechanisms work and the effect that third party billing has on the clinic's budget. Materials specific to the community that explain the budget, the process, and the benefits of public health insurance programs to the people would be useful, as would examples of AI/AN success with programs.
- AI/AN designed programs. Staff recommended that AI/ANs need to take ownership and design programs according to their own cultural needs through innovative funding mechanisms. They believe that it is fruitless in the long run for AI/AN groups to exert time and resources appealing to the Federal and State governments to better serve AI/ANs within the programs that agencies offer to the overall population. Instead, advocacy groups should pursue the creation of programs that are specifically targeted to the AI/AN population.

Outstationed eligibility worker. Staff reported that a County Medicaid worker used to be out-stationed at the clinic and that this was helpful in enrolling people in Medicaid programs. Unfortunately, the on-site position was eliminated due to State budget cuts. Staff suggested that they would like to see the position filled again. They believe that an out-stationed worker is also beneficial to the staff because the County worker can also train staff on programmatic issues. This way, staff will not have to seek out such information. Clinic staff mentioned that CMS had written a letter to State Medicaid offices stating that they should treat IHS facilities in a similar manner to Community Health Centers. Because staff said that the Washington Medicaid program regularly outstations eligibility workers in these Centers, it should also outstation eligibility workers at AI/AN health clinics. Staff said that the State has failed to act upon this letter. Staff also suggested that CMS could consider providing Tribes with direct grants to hire out-stationed eligibility workers. Staff did add, however, that their preference to an outstationed worker would be for the Tribe to have the ability to manage its own Medicaid program and determine eligibility for Tribal members. Staff believe that this would increase enrollment since Tribal members are more trusting of and comfortable with Tribal staff as opposed to County Medicaid staff.

#### FINDINGS: YAKAMA INDIAN RESERVATION

#### Overview

Yakama PHS Indian Health Center serves members of Yakama Indian Nation. While the Health Center remains an IHS facility, the Tribe has contracted with IHS to administer auxiliary health care services such as substance abuse and mental health services. At the Health Center, the site visit team discussed program enrollment barriers and solicited strategies to increase enrollment in Medicaid, SCHIP, and Medicare with the director of the Yakama Service Unit, the business office manager, and two patient benefits coordinators. In addition, staff from Yakama Nation participated in the meeting including: community health representatives; contract health services staff; a home health nurse manager; and, representatives from the Tribe's Health and Human Services Division and Tribal Council. The site visit team also met with the Tribal staff separately from the IHS staff to discuss enrollment barriers from the Tribe's perspective. 409

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<sup>&</sup>lt;sup>409</sup> Prior to the site visit, the BearingPoint site visit team communicated with key contacts at Yakama PHS Indian Health Center and Yakama Nation to set up two separate meetings: one with IHS staff and one with Yakama Nation staff. BearingPoint staff communicated with the Yakama Service Unit Director to coordinate the IHS meeting and with a representative from Yakama Nation's Tribal Council to coordinate the meeting with Tribal staff. On the day of the site visit, Yakama Nation staff attended the meeting scheduled for IHS staff and participated in that meeting. Yakama Nation staff also participated in the meeting scheduled specifically for them. During the meeting with the Yakama Nation staff, representatives from the tribe's Health and Human Services Division and Tribal Council communicated to the site visit team that they considered this meeting to be a preliminary introduction to the project and that additional activities would be necessary for the tribe to consider officially participating in the project. Tribal staff requested that unless they decided to officially participate in the project, no comments from the separate meeting with Tribal health staff were to be included in this report. Because the activities requested by the tribe to be an official participant in the project were outside the scope and budget of the contract, this report does not contain comments made by Tribal staff during their meeting. However, comments made by Tribal health staff during the IHS meeting are included in this report, as these staff chose to attend and participate in this meeting in addition to their individual meeting. As such, "interviewees" and "staff" in this section of the report refer to both IHS and Tribal staff.

Overall, the interviewees felt that under-enrollment in Medicaid, CHIP, Medicare Part B, and the Medicare Savings Programs is prevalent on the Reservation. In general, interviewees noted that fear of eState recovery, lack of awareness about available programs and where to go for help to complete applications, and lack of outreach on the part of the State Medicaid office are significant barriers to enrollment in these public health insurance programs.

Staff cited the need for a better relationship with State and County Medicaid offices, the ability of IHS employees to determine eligibility, increased education about the benefits of public benefits programs for potential applicants, and a more coordinated outreach effort on the part of the clinic and Tribe as the primary strategies for increasing enrollment.

Staff expressed concern that the Medicaid encounter rate for IHS facilities, which serves as the basis of funding for the clinic, is scheduled to be replaced by fee-for-service reimbursement in 2004. Staff fear that if the clinic cannot recoup the full encounter rate, the clinic's funding will decrease drastically.

Staff also expressed frustration about the new Core Provider Agreements (CPA) that the MAA required providers to sign in 2002 if they wanted to become or continue to be Medicaid providers. The CPA is a fundamental agreement that allows physicians and other health care providers to bill the State-Federal program for services and treatments involving Medicaid clients. Staff believe that the new CPA contains language favoring the State that dissuaded many providers from signing it, although they were not able to cite specific language. As a result, many specialist providers who had previously accepted Medicaid patients from the Yakama clinic are no longer seeing any Medicaid patients. Due to a smaller pool of Medicaid providers, patients sometimes have to go to Seattle for Medicaid - covered services that are not available at Yakama.

#### Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

Interviewees most frequently reported the following barriers to initial AI/AN enrollment in Medicaid and CHIP:

- Interviewees reported that fear of eState recovery is a significant barrier for many AI/ANs. Due to historical tension with the Federal government, many AI/ANs fear that if they sign up for public benefits programs, they will eventually have to pay the Federal government back in the form of money, assets, or ancestral land.
- Staff reported that it is difficult for applicants, as well as clinic staff, to understand the different vehicles through which the Medicaid benefits package is available. For instance, children enrolled in Medicaid and CHIP receive the same Medicaid benefits package, but are in the program via different eligibility criteria and may not have the same access to managed care or fee-for-service plans depending on where they live. Also, staff does not feel that a good relationship exists between the clinic and the County Medicaid and local Social Security offices. As such, it is hard to obtain help from them to reduce any confusion about the programs.

- Interviewees cited a lack of transportation to County offices as a barrier to Tribal members who want to enroll in Medicaid, particularly since budget cuts caused the State to close the CSO in Toppenish. Many AI/ANs are either not aware that they can apply for Medicaid by mail or need assistance with the application and do not know where to get help besides going to a CSO. When they are able to obtain transportation to a CSO, many report perceptions of discrimination at CSOs. Word of mouth of this perceived discrimination spreads and deters other AI/ANs from going to County offices to apply.
- Interviewees noted that while Tribal and IHS staff have pro-actively developed networks in Federal, State, and County governments, this type of structure segments communication about and awareness of the barriers, social issues, and trends that affect enrollment within different programs administered, regulated, and/or funded by these different entities.
- I/T/U facilities are not listed as approved PCCMs for many Medicaid managed care plans. Clinic staff feel that this was a result of lack of IHS and Tribal consultation on the part of the State. Interviewees noted that they are in a difficult position. They have spent considerable time and energy to advocate that IHS facilities be certified as PCCMs. Now, with the new CPA, even if IHS facilities were certified as PCCMs with these plans, the clinic will not be able to refer many of these patients for needed specialty care because so many specialist providers have stopped accepting Medicaid patients. Another problem is that since AI/ANs generally prefer to go to an IHS or Tribal facility if the service they need is offered there, the clinic is forced to absorb the cost of the services for patients not enrolled in a health plan for which the relevant IHS facility is a PCCM. In addition, Contract Health Services will not pay for the services because technically the individual has alternate resources.

The Yakama IHS Service Unit Director described this conflict in the Medicaid law in detail. The Yakama Indian Health Center is a PCCM facility. The Yakama Health Center Business Office has been working with patients to enroll them for PCCM as their managed care doctors for Medicaid so that the health center can manage their health care and obtain reimbursement for services provided to them. PCCM facilities are considered the same as "fee for service" and must be registered with Medicaid. As a result of the new CPA, a majority of doctors' offices, and particularly specialists, chose not to sign up as Medicaid providers. This left few choices for referrals for services not available within the Yakama Health Center. The dilemma facing the health center is that providers who accept Medicaid's Healthy Options patients through agreements with certain plans, such the Community Health Plan of Washington, Molina or Premera Blue Cross, can be reimbursed at Medicaid rates by the plan but do not participate in PCCM. PCCM facilities are paid by the State whereas Healthy Options plan providers are reimbursed directly by their respective plans.

Therefore, patients switching to a Healthy Options plan in lieu of a PCCM arrangement must also switch to a Healthy Options provider as their primary care provider, and have their care managed by a doctor who may be unfamiliar with their health history. In addition, Yakama Health Center will not be reimbursed for any services provided to patients of the Yakama Health Center who wish to continue receiving their primary care at the facility, but who must switch from PCCM to Healthy Options in order to receive specialty care. In fact, in this case, the

Healthy Options plan ends up giving Yakama Health Center a referral to see its own patients. Yakama's Service Unit Director noted that this inconsistency in the Medicaid law affects all I/T/U facilities that are PCCMs in Washington State.

• Finally, interviewees pointed out that a lack of definition on the part of the Federal government as to how it would provide health care to AI/ANs has led to much confusion about how AI/ANs should be treated by State and Federal health care agencies. The government promised to provide health care to AI/ANs, but did not say *how* they would do it. During the years of U.S. – Tribal treaties, no public health insurance programs existed so this lack of definition was not an issue. As a result, no regulations exist on how AI/ANs should be treated within programs designed for the overall population. Interviewees said that "AI/ANs are caught between a rock and a hard place." They can obtain numerous and comprehensive services through public benefits programs or fewer and less diverse services through the IHS. Interviewees felt that the government's underfunding of the IHS is the cause of increasing AI/AN enrollment in programs for the overall population. They indicated the onus lies with the Federal government to resolve how AI/ANs can receive services from IHS of the same quality and in the same amount as the overall population receives from public and private sources.

## Barriers to Maintaining Enrollment

- Staff reported that that the periodic redetermination for Medicaid is problematic, and cause many AI/ANs to drop off the Medicaid rolls. Tribal members will sometimes call or come in to see Patient Benefit Coordinators at the clinic if they need assistance with the redetermination paperwork, but this is due to their own initiative. More often than not, Tribal members allow enrollment to lapse rather than deal with the paperwork if they do not have a health situation that requires immediate medical care. Currently, the clinic does not have a "tickler" system in place so staff can remind recipients at redetermination time. If Medicaid rejects a patient's prescription reimbursement, the clinic knows that the individual is no longer on the program and needs to re-apply, but that is after the fact and after a cost to the clinic for the prescription has been incurred.
- Staff also noted that not all Medicaid cards are valid for the same services; that is, some pay for different benefits under different eligibility categories and IHS staff said they need to constantly determine if certain services are covered for particular persons. While DSHS has conducted training on these programs in the past at the clinic, training has always been at the Tribe's request and initiative. Staff feel that they would be in a better position to help people stay on programs if they understood the programs better, and that regular training from the DSHS would help them stay informed about program rules and policies.

#### Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

Staff interviewed said they believe that about 50 percent of Tribal members age 65 or older are eligible for one of the Medicare Savings Programs but that most Tribal members (and some clinic staff) are unaware of the programs. For staff that are aware of the programs, the size

of the Reservation limits the amount of information sharing that can take place. That is, it is problematic getting information about these programs to elders in outlying areas.

Staff believe there is a moderate level of under-enrollment in Medicare Part B, primarily because some Tribal members feel they cannot afford the Part B premium or because some did not enroll in Part B at the time they became eligible for Medicare and a prohibitive penalty has accrued1.

Interviewees cited the following barriers to enrollment in Medicare and the Medicare Savings Programs:

- Another issue mentioned with respect to Medicare and the Medicare Savings Programs is that many Tribal members, both young and old, feel that AI/ANs should not have to apply for public medical assistance programs because of "the Federal Trust Responsibility." As such, one of the significant enrollment barriers for elder AI/ANs who are aware of Medicare and the Medicare Savings Programs is the belief that, because the Federal government is obligated by treaty and law to pay for health care for AI/ANs, they should not have to enroll in programs designed for the non-AI/AN population or be required to pay out-of-pocket for any type of medical care. Exacerbating this situation is a lack of understanding about the facility's funding mechanism and how third party billing would impact this funding mechanism. In fact, some members do not understand that the Tribe and IHS facility are separate entities, and do not understand why they have to enroll in a Federal government program to get health care from what they perceive to be a Tribal entity.
- Lack of reliable transportation is also a significant barrier for many Tribal members who are aware of the Medicare Savings Programs. They are hesitant to enroll because they know they probably cannot secure transportation to actually use these medical services, such as to regularly visit their assigned primary care physician's office.
- Interviewees said that the stigma associated with welfare programs also presents a barrier for some AI/ANs who may be eligible for the Medicare Savings Programs. The fact that some AI/ANs believe they have to go into a CSO office to apply intensifies this reluctance

## Strategies to Increase Enrollment in Medicaid, SCHIP, and Medicare

The interviewees said that while the clinic sponsors a health fair once a year to increase awareness of programs and application assistance from the clinic's patient benefits coordinators, there is need for considerable additional activities to ensure that all eligible Tribal members are enrolled in public insurance programs. These include:

• IHS Determine Eligibility for Public Benefits Programs. Staff would like MAA to offer IHS employees the authority to determine eligibility and enrollment for public health insurance programs. They feel that this authority would make them more credible in informing members about the funding mechanisms for the clinic and why it is important for them to enroll. Interviewees believe that IHS staff already have the

knowledge and capacity to take on this role. In lieu of this authority, clinic staff believe that more out-stationed eligibility workers would help to increase enrollment among Tribal members. The clinic's director stated that the clinic would be willing to share the cost of an out-stationed eligibility worker's salary with the Tribe, thereby covering 100% of the salary of the eligibility worker. While this individual would technically be a State employee, DSHS would not have to pay any of his/her salary.

- One-Stop Information Source of Information on Health Benefits. A "one-stop shopping center" at the clinic staffed with individuals knowledgeable about Tribal, State, and Federal program resources would be effective for increasing enrollment, according to those interviewed. Staff noted that some Tribal members are unaware of resources offered by their own Tribe.
- AI/AN Liaison. Staff felt that AI/AN liaisons (both for clinic staff and for program applicants and beneficiaries) for each Medicaid, SCHIP, and Medicare program would help to increase communication between the Tribes, IHS, and the State and Federal governments.
- Training for Health Facility Staff. Interviewees felt that having trained staff members who are knowledgeable about eligibility issues, understand the enrollment process, and able to help Tribal members complete applications is key to increasing and maintaining enrollment in public health insurance programs. The presence of on-site trained clinic and Tribal staff who can identify and assist potentially eligible AI/ANs through the enrollment process would be an effective mechanism since they are trusted and can more effectively encourage Tribal members to enroll in these programs.
- Culturally Sensitive Outreach Materials. Interviewees stated that culturally sensitive media campaigns such as newspaper advertisements, billboards, a spokesperson who is well recognized within the AI/AN community, public service announcements on Tribal radio stations, and TV commercials and posters depicting AI/ANs would help to more effectively market public insurance programs within the Tribal community.
- Face-to-Face Assistance with Program Enrollment. Interviewed staff emphasized that in-person assistance (both face- to- face and over the telephone) is essential to encourage AI/AN program enrollment. Currently, many helplines for public benefits programs are automated at least to some extent, which deters AI/ANs from accessing these helplines. Interviewees suggested that a culturally sensitive poster with a national 800# that AI/ANs could call to obtain contact information for a local representative to whom AI/ANs could direct questions would be helpful. While it is expensive to make posters unique to local areas, staff suggested that a template superimposed with regional information would work almost as well.
- Utilize Existing Infrastructure to Disseminate Information about Programs. Staff suggested that increased coordination with Tribal outreach staff, such as the public health nursing staff, family resource programs, and elder programs, would help to spread information about public benefits programs to hard-to-reach Tribal members. They believe this type of systematic and regular dissemination of information within the

existing infrastructure would increase enrollment. Staff strongly believe that the best models for outreach and enrollment come from AI/ANs and the means of communication they have already created. The interviewees also remarked that staff in some of these outreach programs are already knowledgeable about public insurance programs, and those that are not can be trained.

Mail-in Application/Self-Declaration of Income. Interviewees did note that the mail-in application and self-declaration of income has been helpful in that it is easier for AI/ANs to follow through on their initial applications. It used to be that a patient at the clinic would be sent to Contract Health if they did not have benefits and then Contract Health would perform a screening and refer the individual to third-party programs. The patient would have to go to a County office, get the appropriate forms and fill them out. Now, patient benefits coordinators can give the forms to the individual after they are screened, and can help them fill out the forms as necessary.

### FINDINGS: SEATTLE INDIAN HEALTH BOARD

## Overview

At the SIHB, the site visit team interviewed the executive director, the associate director, the operations coordinator, and the director of finance. In general, SIHB staff believe there is significant under-enrollment in Parts A and B of the Medicare program among urban area AI/ANs, while estimating that under-enrollment in Medicaid and CHIP is a moderate to significant problem. Staff estimated that about 30 percent of urban area AI/ANs eligible for Medicare Part A and B are enrolled in the program (this statistic is from 2001). A major reason reported for Medicare under-enrollment is a lack of understanding among eligible AI/ANs of the program and how to enroll. Staff also estimated that about 30 percent of urban-area AI/ANs eligible for Medicaid are enrolled in the program, even though 75 percent fall into income categories that may make them eligible for Medicaid. Because the majority, if not all, of the urban-area population (specifically, AI/AN in the Seattle area) is below 200 percent of FPL, very few are eligible for CHIP.

## Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

#### Barriers to Initial Enrollment

SIHB interviewees reported that the main barriers to AI/AN enrollment in Medicaid and CHIP among AI/ANs residing in the Seattle area are:

- There is a moderate level of illiteracy among SIHB's young AI/AN patient population. As a result, some AI/ANs are not able to read and understand written information on the programs and how to enroll.
- Some AI/ANs have reported perceptions of negative experience when visiting CSOs to fill out an application. SIHB staff mentioned that because of the "moccasin telegraph," stories of these perceived negative experiences spread quickly to others, resulting in a feeling of hesitation or fear for other AI/ANs to visit the CSO.

• Staff noted that the turnover of CSO staff and State Medicaid staff is problematic with respect to enrollment in Medicaid and CHIP. Changes in State leadership and local staffing disrupt relationships and agreements between AI/AN advocacy groups and the State and local governments. These disruptions lead to increased confusion about the issues AI/ANs face with respect to public benefits programs as well as break relationships of trust that have been formed between AI/AN groups and State and local administrations

## Barriers to Maintaining Enrollment

• The SIHB staff stated that some AI/ANs enrolled in the Medicaid or CHIP programs are disenrolled from the programs without even realizing it because they are not aware their coverage is up for redetermination. Even though they receive notices from SIHB, many of them are not able to understand when and how they need to be redetermined for the appropriate program. According to SIHB staff, these AI/ANs often do not realize they have been dropped from the programs until they receive a bill for a health care service that they received after the date of loss of coverage.

## Current Enrollment and Barriers to Enrollment in Medicare and the Medicare Savings Programs

According to the staff of the SIHB interviewed, there is significant under-enrollment in the Medicare program among urban area AI/ANs. A fair percentage of Indian clients are not aware that they are eligible for Medicare Part A coverage. SIHB staff assist those who choose to pursue Medicare Part A, although staff noted that their enrollment is not of financial benefit to the SIHB's since Part A covers hospital, rather than outpatient, services.

The staff estimated that only 30 percent of those eligible for Medicare Part B are enrolled, and more than half do not have any other insurance coverage. Interviewees noted the following barriers to enrollment in Medicare and the Medicare Savings Programs:

- Interviewees noted that few SIHB clients purchase Part B services due to cost and copayment requirements. SIHB staff do try to enroll clients in Medicare Part B because the facility would then be eligible to bill for any care provided. However, the cost of the Part B premiums and the spend-down co-pays are not attractive to most of SIHB's lowest income elders.
- Another reason for under-enrollment in Medicare Part B is due to the way that information is communicated to beneficiaries about when and how to enroll. While AI/ANs may receive notices or information from CMS regarding Medicare Part B enrollment, many do not understand the information and do not know where to go for help, or even how to find out where they could receive help. As a result, many of the elder AI/ANs are not aware they need to actively initiate their enrollment before they turn 65, and that if they fail to do so, a penalty will accrue for every year that they do not initiate services. When they do decide to enroll in Part B, perhaps because of an acute health care need, many elders are faced with a prohibitive penalty.

- In addition, a majority of these elders are already enrolled in the Medicaid program and are not aware they may be dually eligible for Medicare and Medicaid at age 65. Because Medicaid covers prescription drug costs, they see little incentive to enroll in Medicare. Staff cited other barriers to Medicare and Medicare Savings Programs enrollment:
- The fact that information on Medicare and the Medicare Savings Program is generally communicated to them in written format is a barrier to enrollment for SIHB clients. According to SIHB staff, their population prefers face-to-face, verbal communication to receive information about the programs.
- There is a lack of understanding of differences in benefits and eligibility criteria among Medicaid, Medicare and the Medicare Savings Programs. Exacerbating this lack of knowledge about the programs is confusion regarding how and when to enroll in Medicare Part B.
- Staff also mentioned Medicaid managed care plans as barriers to enrollment for AI/ANs in Medicaid. Interviewees stated that unless AI/ANs opt out of managed care, they are automatically enrolled in a health plan. At the time of enrollment, the State presents them with several managed care plans as options and most do not realize they can receive their Medicaid services through the SIHB.
- Some AI/ANs feel that enrolling in Medicare or Medicaid programs is essentially "giving up Indian rights," as they feel health care is a Federal Trust Responsibility. As a result, they are reluctant to enroll even if eligible.

## Strategies To Increase Enrollment in Medicaid, SCHIP, and Medicare

Currently, when patients enter an SIHB clinic, they are screened for all forms of insurance coverage and the ability to pay for services on a sliding fee scale based on income level. Patients are asked to fill out a form that identifies any current insurance coverage they may have. Those without any coverage and who are identified by the screening process as potentially eligible for Medicare, Medicaid or CHIP are referred to the clinics' resource advocates, who then determine for which program the patient is potentially eligible. The resource advocates will work with patients to complete applications on-line. However, patients often do not have the adequate documentation necessary for determining eligibility at that time and do not always return later with the necessary documentation. Also, the resource advocates are only able to work with those patients who come in to the clinic for services. There are no funds available to conduct outreach to AI/ANs who do not come into the clinic.

SIHB staff identified the following as possible strategies to increase enrollment in Medicaid, CHIP, and Medicare:

• Additional Resources for Outreach. SIHB staff indicated that increased resources from the State and/or CMS for outreach, such as the placement of additional case managers, outreach workers, and resource advocates, would be helpful for increasing enrollment in the programs. SIHB also said that additional tools for identifying and enrolling potential eligibles as well as training in the basics of the different options and respective

eligibility/enrollment issues for AI/ANs would help staff be more effective in increasing enrollment. Staff also suggested that CMS could provide more outreach, or support for outreach, for Medicare, similar to what Washington State has done for CHIP awareness and enrollment.

- AI/AN Liaison/Increased Coordination with Local Medicaid Office. Currently, SIHB staff maintain a strong relationship with the CMS regional office and the State level of the DSHS office. However, SIHB staff feel that closer and more direct contact with a designated representative/liaison from the local DSHS office would be a good strategy for increasing enrollment of eligible patients in these programs. There are 11 CSOs in King County (the County that encompasses the Seattle metropolitan area), and the AI/ANs living in this County are geographically dispersed throughout the 11 service areas. Because some CSOs are operated differently than others, confusion and differing priorities about enrollment exist. As such, a designated DSHS liaison would ideally be available for SIHB staff to assist them with enrollment issues specific to each CSO area.
- Outstationed Eligibility Worker. Although the SIHB is a Federally Qualified Health Center, the clinic's patient volume is too low to qualify for an eligibility worker on-site. SIHB staff feel having an on-site eligibility worker would help to increase enrollment in Medicaid and CHIP. Because many of their patients have a limited ability to read and understand complex information, additional one-on-one counseling would help increase enrollment. One suggestion raised by staff was to develop a cost-sharing arrangement with DSHS to hire an eligibility worker at the clinic and/or consider allowing eligibility determination to be conducted at the clinic.
- **Simplified Education Materials.** Elder AI/ANs need simple, easy to understand materials on when and how to enroll in Medicare. Although AI/ANs may already be receiving such information, SIHB staff believe the information is confusing and not easy for the elders to understand. As a result, many eligible AI/ANs are not enrolled in Medicare.
- **National Medicaid Package.** SIHB staff suggested that the development of single, national Medicaid package for AI/ANs would help alleviate the feeling that they are "giving up rights" that were promised to them, since there would be a separate eligibility determination and enrollment process for AI/ANs.
- Linked Data. CMS could consider linking Medicaid, SCHIP, and Medicare data with IHS patient registration data to improve the development of baseline data and the ability to measure the impact of outreach and enrollment efforts for AI/ANs. This would help AI/AN health care facilities such as SIHB to more accurately benchmark enrollment levels at the clinic against enrollment levels of other AI/AN populations.
- Redetermination Notification Sent to Health Facility. Currently, DSHS notifies patients directly when they are due for redetermination. SIHB staff felt that if the clinic could receive concurrent notice from the State for these patients, they could then work to ensure that more AI/ANs are able to maintain their enrollment in the Medicaid and CHIP programs.

• Require HMOs to Contract with Urban Indian Health Clinics. Interviewees noted that SIHB, like all FQHCs, are precluded from contractual relationships with HMOs. Staff recommended that CMS require HMOs to contract with all FQHC clinics in the area. However, CMS should require that this contract be non-risk-bearing to the FQHC clinic. While such an arrangement is most likely not possible for a for-profit HMO, staff believe that a not-for-profit HMO could be an exception.

#### FINDINGS: OTHER ORGANIZATIONS

## <u>Overview</u>

The Washington Health Foundation was awarded a grant from Robert Wood Johnson Foundation's (RWJF) Covering Kids Initiative (described earlier in the report) in 1997. The pilot project, initially funded by a three-year grant, was extended until 2005 through a follow-on grant from RWJF. The site visit team conducted telephone interviews with some of the staff involved with the Covering Kids pilot project in Washington State: Katy Burchett, Statewide Coordinator for Washington's Covering Kids Initiative; Rosemary Espinoza, outreach worker for Washington's Covering Kids Initiative; Emma Medicine White Crow, Program Manager for Rural Tribal Health for the Washington Health Foundation; and Rudy Vasquez, Community Coordinator for the Washington Association of Community and Migrant Health Centers.

Interviewees reported that significant differences exist in the levels of Tribal collaboration with the State, as well as differences in the magnitude that program enrollment has increased across Tribes. Staff noted that the level of Tribal collaboration with the State is directly related to how much enrollment increases in the Tribe.

## Current Enrollment and Barriers to Enrollment in Medicaid and SCHIP

Pilot project staff said they encountered the following barriers to enrollment for AI/ANs in Washington's Medicaid and CHIP programs:

- Because of a high staff turnover in some Tribal health centers, CHIP and Medicaid enrollment suffers as the level of understanding of program enrollment criteria waxes and wanes. Turnover is attributed mostly to fluctuations in funding.
- Many rural Community Health Centers do not have the luxury of a specific staff person whose primary function is to conduct outreach. Typically, someone simply assumes outreach duties on top of his/her daily responsibilities. When the clinic gets busy, outreach is not a priority. Also, when someone does get trained, replacing him/her is very difficult should they ever leave. Typically, rural health care clinics conduct more "inreach" than outreach. That is, patients must come to the clinic for face-to-face information. This is due to the lack of funding for a specific outreach worker in remote areas of the State.
- At the time of the pilot Covering Kids project, the State sent an outreach worker to conduct training at area clinics once every several months. Due to staff turnover, however, this training schedule did not lend itself well to meeting the needs of clients

with immediate health care coverage issues. To compound this challenge, in some clinics a fax machine was the only means of communication between their clinic and the State. As a result, outreach information was not well distributed to internal staff, nor subsequently to external audiences.

• In some remote areas of the State, travel to clinics can often be a two-hour drive. Some Tribes have applied for grants to assist with bussing services on Reservations, but access to this service is neither uniform nor sustainable in the long term. Also, successful program development is often dependent on a skilled grant writer and not all Tribes have equal access to one.

## Strategies To Increase Enrollment in Medicaid and SCHIP

Covering Kids pilot staff provided the following enrollment strategies and best practices to increase AI/AN enrollment in Washington's Medicaid and CHIP programs:

- Outreach Materials Depicting AI/AN Children. The State has an internal working group that developed posters depicting a diverse group of children, including two posters with just AI/AN children dancing at a pow-wow. To further draw attention to these posters, the children in the pow-wows are all local. Pilot staff felt more of this type of culturally sensitive outreach material development is needed to catch AI/AN attention and encourage them to enroll in the programs.
- Outstationed Medicaid Eligibility Workers. The State had out-stationed CSO staff at several Tribal offices. This not only enhanced the collaborative relationship between the Tribe and the State, but also eliminated a barrier to enrollment by increasing access to information and assistance.
- **Dedicated AI/AN Liaison.** The State has a dedicated MAA staff person to work with the AI/AN community on enrollment in CHIP and Medicaid, although it is available in urban settings only. This person drafts press releases and helps conduct outreach events at local clinics and any other community event where potential applicants may attend. Covering Kids found this outreach worker to be invaluable.
- **Public Service Announcement Promoting Programs.** Through an overlay using "Photo-Shop," the Governor participated in a public service announcement with local AI/AN children during the time of the pilot project. This outreach effort was useful not only in promoting CHIP, it also helped enhance the level of trust between State government and the AI/AN community, according to the pilot staff interviewed.
- Committed Outreach Staff. Hiring the right outreach worker i.e., one that is articulate, persistent, and truly committed to the mission can lead to success surpassing that of any other outreach campaign or method of enrollment. If that outreach worker has some input in the development of outreach methodology and goal setting, their success will be even greater.
- **Face-to-Face Outreach**. One-on-one interaction is, by far, the most effective means of outreach for CHIP and Medicaid for AI/ANs, according to the pilot staff interviewed.

#### DISCUSSION

Overall, Washington site visit interviewees consider under-enrollment in Medicaid, SCHIP, Medicare and the Medicare Savings Programs moderate to significant problems for Reservation-based AI/ANs and urban AI/ANs in Washington. The barriers most frequently cited by all interviewees include:

- Lack of incentive to enroll. Among those AI/ANs who are aware of the programs, many choose not to enroll because they feel they already have access to IHS and Tribal health services and therefore perceive no added benefit to enrolling. Many also strongly believe that the Federal government has promised them health care and that they should not have to enroll in programs intended for the overall population or for individuals who fall within certain income guidelines to receive that care. In addition, some AI/ANs also have a general feeling of mistrust towards the government. Finally, others simply lack awareness of the programs and/or program benefits. All of these factors combined result in disincentives for members to enroll.
- The Federal Trust Responsibility. According to interviewees, many AI/ANs perceive that the Federal Trust Responsibility implies that all AI/ANs should have access to medical care through the IHS based on their status as a Tribal member. They should not have to prove eligibility for services by filling out enrollment forms that may require income, asset, and social security information, and periodic paperwork to re-verify eligibility. Interviewees said that the requirement to "prove" eligibility is philosophically opposed to the Federal Trust Responsibility, which is perceived to guarantee health care without the need for dealing with the bureaucracy of public insurance programs that were not designed especially for the AI/AN population.
- Perceived stigma. According to those interviewed, the persistent stigma associated with the use of Medicaid and CHIP programs is also an issue. Medicaid and CHIP eligibility are based on income criteria and viewed by some as welfare programs. Many AI/ANs do not want to accept health care through a means-tested program intended for low-income populations when they believe that the obligation of the Federal government is to provide health care to them based on their AI/AN ancestry. While the resulting health care may be the same whatever the source and whatever the funding mechanism, the financial origin of care is an issue of principle and pride for many AI/ANs. Interviewees said they are accustomed to receiving services based on their status as a member of a Tribe, which is a source of pride. Once they are required to enroll in a public health insurance program, income and socioeconomic status become part of the health care delivery system. While this may be common in the non-AI/AN population, it is not as familiar or acceptable a concept in Indian culture, according to interviewees.

Based on the reported enrollment barriers, key recommendations provided by the interviewees include:

• Outreach and Education. Everyone interviewed agreed that there is a need for more consumer and community outreach and education about all of the programs. The majority of the Tribal members do not understand that enrolling in these programs will result in

increased financial resources, or more efficient use of Tribal resources, and will benefit their Tribe as a whole. Tribal staff felt that if members understood this concept better, they might be more motivated to enroll. All clinic staff interviewed – both in Tribal and urban facilities – said they could benefit from additional resources to hire more Patient Benefits Counselors and Community Health Representatives, which would support more one-on-one assistance both within and outside of health facilities to eligible AI/ANs. Benefits counselors and Community Health Representatives could spend more time educating AI/AN communities about the programs and the benefits of enrolling, assisting with transportation issues, and facilitating and providing follow-up with enrollment and redetermination processes.

- On-site determination. Tribal and IHS staff suggested that their ability to determine eligibility on-site (either by their own staff or by a County CSO eligibility worker) would likely result in a marked increase in Medicaid enrollment.
- Consumer education. Consumer education about the benefits of the programs, including increased awareness that greater enrollment in Medicare, Medicaid, CHIP, and Medicare Savings Programs frees up Tribal funds for additional services, would help to increase enrollment in public benefits programs. Interviewees indicated that the majority of the information currently available is complex and difficult to understand for AI/ANs. Educational materials should be simple, easy to understand, and culturally appropriate.
- Additional funds. Additional funds for Tribes so that they can hire more Tribally-based staff to provide more outreach, education, and assistance to Tribal members in enrolling and maintaining enrollment would help to increase enrollment in these programs. Interviewees stated that the most effective form of communication with AI/ANs is through face-to-face discussions. However, staff currently do not have the time to provide effective one-on-one education and assistance to members.
- Identify designated liaisons from DSHS and/or provide on-site DSHS eligibility workers. Interviewees mentioned having a direct contact with a designated representative/liaison from the local DSHS office would be a strategy for increasing the enrollment. This designated DSHS liaison would be available to help staff work through specific enrollment issues. Interviewees also felt having an on-site eligibility worker would also help increase enrollment.
- **Program Training**. Interviewees stated the need for additional and on-going training on the basics of the different options and respective eligibility/enrollment issues for AI/ANs. Many staff members interviewed were themselves not aware of all of the issues and indicated a need for more training. Because aspects of the programs often change, staff need frequent and on-going training to keep abreast of updates and to be better prepared to explain the changes to members.

# APPENDIX XI.A: WASHINGTON SITE VISIT CONTACT LIST

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# APPENDIX XI.B: TRIBAL POSITION PAPER ON TRIBAL CONSULTATION DRAFTED BY LUMMI NATION

## Tribal Position Paper on Centers for Medicare and Medicaid Services Tribal Consultation

(submitted to CMS and DHHS on December 6, 2002)

The Centers for Medicare and Medicaid Services (CMS) is required by Executive Order 13175 on *Consultation and Coordination With Indian Tribal Governments* to engage in Tribal consultation. This order was re-affirmed by President Bush in a letter from Alberto R. Gonzales, Counsel to the President, to engage in Tribal consultation. To comply with this order, it is essential that policy and technical decisions are made with full knowledge of the impact on access to health care for American Indian and Alaska Native (AI/AN) beneficiaries. CMS uses the following Department of Health and Human Services (DHHS) workgroup definition of consultation:

"Consultation is an enhanced form of communication which emphasizes trust, respect and shared responsibility. Consultation is integral to a deliberative process which results in effective collaboration and informed decision making."

Currently, CMS uses several mechanisms for communications with Tribes. These include Dear Tribal Leader letters, comment periods on proposed regulations, a website, and the designation of a Native American Contact person in each CMS Regional Office. However, these mechanisms are insufficient to resolve many issues that are currently impacting Indian health care consumers and providers. Tribal consultation requires effective communication before, during and after policy decisions that may affect Tribes. To accomplish this, recognized national Tribal consultation groups are essential to provide the consensus building processes necessary for the development of Federal laws, regulations, and policies that affect all Tribes.

This position paper outlines a process of Tribal consultation that adheres to the principle of government-to-government relationships as a matter for Tribal leadership, and also responds to the need for the resolution of highly technical issues by involving experts in AI/AN health care who are accountable to Tribes.

The CMS's Consultation Strategy published on its website States, "CMS shall consult with Tribes about communication methods" and acknowledges that "consultation is viewed by CMS as an evolving process." The next step in this evolution should be the immediate implementation of a CMS technical group and broad Tribal consultation on the mechanisms for national consultation.

#### **Background**

CMS currently has a technical advisory group of State Medicaid directors who provide input on Indian health issues, but Tribes and the Indian Health Service (IHS) are not represented in those discussions. There is also an internal IHS/CMS Steering Committee, which does not have Tribal

representation and has rarely met for the past two years. There has been much discussion about CMS having a separate Tribal Technical Advisory Group, but this has not been implemented.

The last communication with Tribes about establishing a Tribal Technical Advisory Group was on January 8, 2001, when Linda A. Ruiz, Regional Administrator for Region X and the lead person for field activities related to AI/AN in CMS, sent to Tribal leaders a draft charter for a National Tribal Technical Advisory Group (NTTAG). Several Tribes responded in support of the concept, but they suggested some changes to the draft charter, primarily related to the selection of members and ensuring that CMS directly address the Federal Trust Responsibility. Tribes also stated that they wanted to select their own representatives to participate on CMS committees and that Tribal representatives may or may not be elected Tribal leaders.

The current Consultation Policy on the CMS website States: "Identification and resolution of issues will take place largely at the Regional level." The policy published on the website makes no provision for a national advisory group.

In the absence of a National Technical Advisory Group (TAG), Tribes have formed an ad hoc TAG. The National Indian Health Board (NIHB) passed a resolution in January 2002 authorizing this group to work on behalf of Tribes on the pressing issue of implementation of the OPPS in Medicare. However, it is costly for this group to meet and Tribes cannot afford to continue to support the effort. New issues arise weekly that indicate a need for an expanded effort of communications, analysis, and policy development.

#### **Need for Additional Tribal Consultation**

Fundamental to Federal Indian policy is the government-to-government relationship that provides the opportunity for each Federally Recognized Tribe to be consulted on major policy issues. While some Tribes prefer individual meetings with government agencies, most Tribes recognize that this is not always feasible with more than 560 Tribes. Thus, Tribes generally have accepted an approach that involves periodic regional and national meetings between Tribal leaders and high-ranking Federal officials to resolve major policy issues. Still, government-to-government relationships demand that each Tribe is provided with information about Federal policy issues and changes and has the opportunity to directly communicate its views.

To assist in focusing on issues for Tribal consultation, there is a need for a representative group of elected Tribal leaders to have on-going communications with the leadership of the DHHS regarding broad policy decisions. This smaller group is needed, to ensure that effective collaboration and informed decision-making with Tribes occurs before, during, and after CMS policy decisions are made. This would be analogous to a group of State governors with a keen interest in health and human services meeting with the Secretary of DHHS and other high-ranking officials one or two times per year. For the purposes of this paper, we will call this the Tribal Leadership Group (TLG).

To support the TLG, there is also a need for a special technical group to analyze specific issues. This would involve Tribal health directors, Tribal business office personnel, and consultants, all of whom are accountable to Tribes. This group would meet with the technical staff of CMS to

work out issues related to specific issues or problems created by CMS or State Medicaid policy decisions. This is analogous to Medicaid Directors meeting with CMS staff. Because there are so many unresolved issues regarding service to American Indian and Alaska Native beneficiaries of Medicare, Medicaid, and Child Health Insurance Programs, this technical group may need to meet frequently, perhaps 4 to 6 times per year in the beginning. For the purposes of this paper, we will call this the Tribal Technical Advisory Group (TTAG). The TLG would work closely with the TTAG to ensure that Tribal issues are effectively raised, addressed and resolved.

#### Selection of TLG and TTAG

There is an established method of selecting representatives to develop national consensus on Federal policies related to Indian health care. The Indian Health Service (IHS) is divided into 12 administrative units called "Area Offices." The Tribes within each of these Areas meet regularly, usually under the auspices of an Area Tribal Health Board. In IHS Areas where the Area Tribal Health Board does not represent all Tribes in the Area, the IHS Area Director holds meetings with all Tribes. At these meetings, the Tribes select their representatives for various national advisory groups. These Areawide meetings also provide a venue for the Tribal representatives to report back to the Tribes in the Area and to seek their positions on various issues, often through a formal resolution process.

Both the TLG and the TTAG would be expected to have at least 12 members, one from each IHS Area. Additional members would also be needed to assure that a full range of information is presented in the decision-making process.

The TLG might also include representation from national Indian groups, such as the National Indian Health Board (NIHB), the National Congress of American Indians (NCAI), and the Tribal Self-Governance Advisory Committee (TSGAC). IHS workgroups usually also include a representative of the National Council of Urban Indian Health Programs.

The TTAG might need additional members to assure that subject specific expertise is available. For example, it is possible that none of the technical representatives selected by the Areas would have expertise in long term care issues. Additionally, one Area may have two national experts on issues related to CMS. Therefore, the TTAG might need to add 3-5 members with expertise not already represented in the group.

It must be acknowledged that initially most of the TTAG members are not likely to be enrolled members of Federally Recognized Tribes. They will have accountability to the Areas that select them, but there may be a need for additional accountability. One way to do this is to have a linkage between the TLG and the TTAG. For example, the TLG could appoint the additional members needed for the TTAG.

It might be helpful to have staggered terms for both the TLG and the TTAG. A limited term, such as two years, might encourage Tribal leaders and others to make a commitment to this type of service. Staggering terms would provide some continuity. It is easier for Tribes to consider reappointing representatives after their term expires, rather than removing people from service if they are not doing a good job or there is a better representative. There could also be a mechanism

for automatically removing people from the committees if they fail to attend a specified number of consecutive meetings.

Other linkages between the TTAG and the TLG might be helpful. For example, a TLG member could serve on the TTAG and report back to the TLG. The TTAG could provide minutes of its meetings to the TLG. The chair of the TTAG could make regular reports to the TLG. These mechanisms would assure that elected Tribal officials are in control of the overall process and are actively participating in identifying issues that need broader Tribal consultation.

#### **Matching Issues to Consultation Approaches**

With State Medicaid Directors meetings, CMS has a working model that currently involves routine consultation on policy changes that is also appropriate for the TTAG. It is the duty of these groups to participate in analysis, discussion, and wording of potential policy changes.

In addition, the TTAG will be assisting CMS in identifying issues that should be referred to the TLG. The TLG could choose from a variety of protocols, including: 1) the TLG could ascertain that there is a high degree of national consensus on the issue and speak on behalf of Tribes without further consultation; 2) the TLG and the TTAG members could go back to the Tribes in their Area to inform them about the issues and to poll Tribes informally or use a formal resolution process for Area positions, returning to the TLG for a national consensus position; or 3) the TLG could request that CMS hold formal consultations with Tribes at the regional and national levels.

## TLG as an Umbrella Advisory Group for DHHS

The TLG is envisioned as an umbrella advisory group for the "One DHHS." It could deal with issues that cut across the eleven agencies in DHHS. It could recommend additional TTAGs for agencies other than CMS. For example, there could be a TTAG for the Centers for Disease Control and Prevention (CDC) that reports to the TLG in the same way as the CMS TTAG.

This is not a new idea. The mechanisms for an "Intra-Agency Council on Native American Affairs" were developed in concept, but never implemented.

### **Implementation of These Concepts**

It seems clear that there is Tribal support for the concept of the TTAG and TLG. This has already been endorsed by the NIHB, NCAI, and TSGAC. There has been an opportunity for Tribes to review and comment on this position paper. The need is so great that CMS should move forward on this as quickly as possible. Changes can be made later if Tribal leaders request modifications.

CMS has the authority to establish the TTAG, and DHHS has the authority to establish the TLG. According to the CMS website as of September 30, 2002, responsibility for decisions regarding Tribal consultation is assigned as follows:

Responsibility for ensuring the consultation strategy is implemented, maintained, and continually improved and adapted to change, is vested in a joint partnership between CMS's

headquarters and its regional offices. The Intergovernmental and Tribal Affairs Group (IGTAG), the Director of the Center for Medicaid and State Operations (CMSO), and the Regional Administrators with Seattle as the lead for all field activities, share joint responsibility for establishing effective communication mechanisms with Tribes and for ensuring effective ongoing consultation with Tribes.

Thus, it is recommended that CMS hold the first TTAG meeting by the end of January 2003. It is further recommended that a TLG meeting be held by the end of February 2003.

Initial tasks of the TTAG would include: revision of CMS Tribal Consultation Policy Implementation, resolution of OPPS Policy Issues, and setting an agenda for additional issues to be addressed by TLG and TTAG. Of particular interest in the consultation process is the structure of the TLG and TTAG and how these groups should function.

This position paper was developed consistent with resolutions adopted by the National Congress of American Indians and the Tribal Self-Governance Advisory Committee.

/s/	/s/
Bernard Bouschor, Chairman	W. Ron Allen, Chairman
Sault Ste. Marie Tribe	Jamestown S'Klallam Tribe
/s/	/s/
Buford L. Rolin, Vice Chairman	Greg E. Pyle
Poarch Band of Creek Indians	Choctaw Nation
/s/	/s/
Julia Davis-Wheeler, Secretary	Tex G. Hall
Nez Perce Nation	
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